

# **DISABLED PEOPLE'S HEALTHCARE ENCOUNTERS**

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## **DECLARATION**

I declare that this thesis is entirely my own work and that it has been submitted only for the degree of Ph.D.

Signature .....

Ruth Bailey

28 February 2009

## **Abstract**

This thesis is about impairment, disability and health. Placed in the context of Disability Studies, it engages with the theoretical debates about how disability and impairment should be conceived. In doing so it pays particular attention to the embodiment of impairment and its relation to health matters. It also identifies and discusses the reasons for the apparent reluctance of Disability Studies to engage with health issues.

The main source of data is interviews with 28 disabled people from Edinburgh and the Lothians. Using semi structured interviews, participants were encouraged to talk about their experiences of using healthcare including the access barriers they faced, the expertise they developed to manage their health care encounters and how these encounters mediated and were mediated by their lived experience as disabled people. A secondary source of data is autoethnographic writing. Through reflexivity, an assessment is made of the value and validity of using this method to explicitly incorporate the researcher's own experiences in to the data and its analysis. Similarly reflexivity is deployed to consider the methodological issues that arise from the researcher being disabled and encountering access barriers during the research process.

There were three sets of findings from the research. First, participants' body talk suggested that in everyday life impairment and maintaining good health can be understood as something which is done by the embodied self to the body. This doing is often a taken-for-granted activity. It is also mediated through a number of factors including emotions, disabling barriers and broader social and economic structures. Second, participants' accounts of the access barriers they faced when using the NHS suggested that there are two categories of access needs, the macro and micro. While macro needs such as ramped or flat access to premises were anticipated and routinely met without participants having to take any action, participants often felt they had to take the initiative to ensure their micro needs, such as the need for a hoist, were met. Some micro access needs were particular to a healthcare context and often emerged

during diagnostic tests or treatment procedures. Healthcare professionals had to have sufficient skills and confidence to respond effectively to these clinical micro needs.

The third set of findings was that some participants developed expertise to enable them to access the appropriate services to meet their needs and form a high quality relationship with healthcare professionals. However, other participants recalled situations where their expertise was not respected and felt abandoned by the NHS.

The first set of findings has implications for theoretical development in Disability Studies. More work is needed to connect the doing of impairment to theoretical approaches found in sociology of the body and to empirically explore the nature and scope of impairment doing. The second and third set of findings have implications for current healthcare practice particularly in the context of the NHS' responsibility under the Disability Discrimination Act.

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# INTRODUCTION

As a disability activist in the heady period of the late 1980s and early 1990s, the social model of disability became deeply embedded in my psyche. As we shall see, this model posits that the problems disabled people face are rooted in the way society is organised rather than in their bodies, as suggested by the individual model of disability. The seeds of this thesis were sown during an acute illness and protracted recovery when neither the social nor the individual model of disability had much to say that was pertinent to my experiences. How then could I make sense of this at a political or sociological level?

The possibility of an answer to this came when I had the great fortune to stumble across an advertisement for The ECAS Centenary PhD Scholarship on the theme of disability and health. Informed by personal experiences, my application proposal focused upon three questions:

- Why hadn't health issues figured on the disability movement's agenda?
- Is there always a difference between being ill and being impaired?
- Could the social model of disability be applied to healthcare settings?

Variations on these three questions have been the dynamic of this PhD and are reflected in the goals and structure of this thesis. Simply stated, the aim of this thesis is to understand the social factors that shape disabled peoples' use of healthcare services in Edinburgh and the Lothians and to consider what this tells us about disability and impairment. To achieve this, my first objective was to review how disability and impairment have been conceptualised and their theoretical relationships with concepts of health, illness, biomedicine and medicalisation. My second objective was to undertake an empirical study of disabled people's health care experiences. I hoped the first objective would be a valuable contribution to the literature and provide the context within which to place the study. In turn, I hoped my research findings could be used to comment on the conceptual debates.

To achieve my aims and objectives this thesis proceeds as follows. Chapter one uses the question about the disability movement and health as a way to explore the

ongoing debates on how the experience of disability and impairment should be conceptualised and theorised. It is, I think, fair to say that this debate has also involved acknowledging that, while the social model of disability just about remains the perfect campaigning tool, for the purposes of academia something more is needed to capture the detail and diversity of disabled people's experiences. Throughout the life of this PhD, I too have had to make this acknowledgement which has been easier at some times than at others. This probably helps to explain that at numerous points in this thesis I talk about the need to hold the tension between competing ideas and interpretations.

At the end of the first chapter and in the second I begin to unpack my second question, the relationship between illness and impairment, and try to bring health in to that equation too. In doing so, I want to highlight the similarities and differences between these concepts.

Chapters three and four seek to understand what the social model profoundly challenges: medical interpretations of disability and impairment. Chapter three looks at the meanings of disability and impairment embedded in medical knowledge, while chapter four considers how these meanings have been woven into the fabric of society through the processes of medicalisation.

Chapter five tells the story of the struggle to turn my three questions outlined above into a viable empirical research project and the thinking behind the journey from research proposal to data analysis. Chapters six to eight present the fruits of this process. At times during the research I regretted not limiting my research to one particular group of disabled people or aspect of the health service. However, with heartfelt thanks to my participants and the rich and diverse experiences they shared with me, in the end I saw this as a strength which enabled me to engage with a range of issues which shed light on the questions above. Specifically, chapter six uses the concept of "doing impairment" to make sense of what disabled people have to do to live through an impaired body in a disabling world. It provides another, non medicalised way of exploring what is usually called managing impairment. It does so by turning around a question which has stayed with me for nearly thirty years.

This was posed in a Disability Arts In London magazine, alas long thrown away: what, Sian Vasey asked, do non-disabled people do all day if they don't have to arrange for a Personal Assistant to come and get them up, if they don't need to make half a dozen calls to get what was then a rare beast a wheelchair accessible taxi to take them to work, if they don't have to explain to a work colleague why they need a hand off with their coat and so forth?

By using the concept of doing impairment, I want to look at what it is that disabled people *do* that says neither "poor me" for having to do this nor discounts it as nothing in a bid to claim equality with non-disabled people. This theme is continued in chapter seven and eight. The former looks at one particular form of *doing disability* that is handling access barriers in healthcare contexts. Chapter eight then looks at participants' expectations of support from the NHS and how they do healthcare in order to access appropriate services and manage relationships with healthcare professionals.

# CHAPTER 1

## Disability, Impairment and Illness

### *Introduction*

In this chapter I want to provide the academic context within which this thesis seeks to understand disabled people's experiences of health care. To do this it will give an overview of ongoing debates within Disability Studies about conceptualising and theorising disability and disabled people's experiences. Particular attention will be paid to how this theorising and conceptualisation has given rise to a noted reluctance (DeJong & Basnett, 2001, Begum, 1996, Shakespeare, 2005) on the part of Disability Studies scholars to engage with health issues. This reluctance, I will suggest, has emerged from the need to challenge dominant medical views of disability. Finally I will consider the similarities between impairment and illness.

### *Two Models of Disability*

To begin, I want to sketch the origins of the social and individual models of disability. This will provide the foundation for considering debates about theorising disability and impairment in greater depth.

Disability Studies was founded upon an understanding of disability as a social and political issue, not a medical one. The basis for this was the thinking of the Union of the Physically Impaired Against Segregation (UPIAS), which in the 1970s was one of the first political organisations of disabled people. It regarded disability as 'the disadvantage or restriction of activity caused by a contemporary social organization' which was imposed upon impaired people (Oliver, 1990a:11). For UPIAS, disability was a social phenomenon which could be distinguished quite clearly from impairment, which it defined as 'lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body' (11). The purpose of making this distinction was political rather than theoretical, it was to highlight the 'need for urgent change', instigated by the state, to enable disabled people to live independently and gain employment (Oliver, 1996a:24) and so be able to participate in society.

As a means of clarifying the UPIAS distinction between impairment and disability and underlining its significance, Oliver (1996a) proposed two models of disability, the social and the individual (the latter is also known as the medical model). The social model embraces the split between impairment and disability and conceives disability in terms of socially created barriers which systematically exclude disabled people from mainstream society. The whole thrust of the disability movement has been to identify and campaign for the removal of these barriers. Taking this stance was a deliberate rejection of the individual model of disability which was the pervasive or 'natural' view. That model regarded disability as a problem caused by the 'functional limitations or psychological losses' of the individual (Oliver, 1996a:32). From this perspective, disability was seen as a personal tragedy and state action in the form of welfare was required to compensate for it.

Both of these models now contribute to public discourses of disability (Jolly, 2003), yet the social model was only intended to provide a *starting point* for discussions of the social forces which lay behind disabled people's exclusion from mainstream society (Tregaskis, 2002). A major and founding contribution to this discussion was the theoretical work of Oliver (1990a) who sought to provide an account of how disability was (and is) produced by the social and economic relationships characteristic of capitalism. To do this, Oliver draws upon a materialist framework which seeks to explain social phenomena with reference to, on the one hand, the historically evolving relationship between the social and cultural environment, and on the other, the mode of producing and distributing goods to meet human needs. Using Finkelstein's (1980) idealised model of historical shifts in the mode of production, Oliver argues that with the emergence of industrial production in the 19<sup>th</sup> Century, disabled people were no longer able to contribute to economic production. This was because the new industrial production process was physically arranged to be used by the standard male, unimpaired worker (Gleeson, 1999): disabled people were excluded from the workplace because their impaired bodies literally didn't fit in to this process Oliver (1990a). This contrasted with the former, agricultural mode of production, where the productive unit was the family, not the individual. This mode could accommodate those disabled people who worked at a slower pace or could fulfil part of the productive task.

According to Oliver (1990a) this exclusion was controlled by medicalising disability. The emerging medical profession took on the role of certifying those unable to work. It did so by ascribing the cause of this inability to the pathology of the individual, not to the inaccessibility of the workplace. In other words, this was the origin of the individual model of disability: the cause of workplace exclusion was seen to lay with the individual and the medical profession assumed a position of power over disabled people to define those who could not work and to control access to the limited poor law relief for those considered the 'deserving poor'.

This medicalisation of disability and the biomedical views of disability which underpin it will be explored in more detail in following chapters. Here, even from this sketch of the founding theoretical underpinnings of the social model, two points can be made about Disability Studies' reluctance to engage in health issues. First, in effect, Oliver implicates the medical profession as instrumental in the continuing reproduction of disability which occurs through the practice of medicalisation. In the context of this argument, engaging with health issues is seen as risky because it reinforces the idea that impairment is a health issue (Barnes, 2003). Second, from Oliver's (1996a) account of the production of disability, we can begin to see how he has claimed, albeit somewhat polemically, that 'disablement has nothing to do with the body' (35). The detail or nature of the impaired body is of no interest to Oliver's theorising: the problem of disability is the social and cultural response or lack of response to the needs and abilities of those citizens who have an impaired body. From this view, as Shakespeare (2006) points out, impairment is little more than a pre-condition of encountering disabling barriers. Without a body, or at least, some of its parts, it is difficult to talk about health issues as health, along with impairment and illness, are *inter alia*, bodily states.

However, it is perhaps useful to point out there are *traces* of the impaired body in Oliver's work. The social model is all about bodies in relation to social space. This politicised the concept of space, showing it to be contingent upon social relations rather than something given, neutral: as we saw above, disabled people's exclusion from the industrial workplace rested upon it being inaccessible to those with an impaired body. The problem, however, is that in Oliver's theory the body is too

abstract to allow detailed analysis of the relationship between particular impaired bodies and the particular disabling spaces that form the backdrop to disabled people's everyday experiences (Freund, 2001). Further, as Thomas (1999) has pointed out, Oliver does acknowledge the bodily reality of impairment but splits it off from the political and consigns it to the 'private' realm of personal experience. This is politically expedient on two counts. First, the priority for Oliver is the collective struggle for barrier removal which is well served by the simple and unambiguous slogan 'we are disabled by society not our bodies' (Shakespeare & Watson, 2001) which has made for good and perhaps necessary political rhetoric. Second, Oliver sees little point in considering impairment because nothing can be done about it. Hence impairment is 'nothing less than a description of the physical body' (Oliver, 1996a:35).

Yet this description is ultimately a biomedical one (and originally excluded mental health survivors and those with learning difficulties). It talks about impairment in terms of what the body lacks. Hence the social model and Oliver's materialist theorising has 'conceded impairment to medical hegemony' (Hughes, 2002a:67), thus making it harder to engage with health and illness issues outwith a medical framework. However, the social model and theorising disability has been substantially developed over the nearly twenty years since Oliver published his seminal work *The Politics of Disablement* (1990). Have these developments facilitated an examination of disability and health? I will explore this next question by charting the shifts in thinking about the disability/impairment dichotomy which is at the heart of the social model. Doing this will provide insight into understandings of the impaired body, which, as Shakespeare (2005) has argued, is a pre-requisite of exploring health and medical issues within Disability Studies.

### ***Challenging the Impairment/Disability Dichotomy***

#### ***Feminist Challenges***

The precursor of direct challenges to the impairment/disability dichotomy came from disabled feminists who argued that disabled people's situation could not be explained adequately with reference to disability alone (Crow, 1992, French, 1993, 1999b,



Morris, 1991): the subjective experience of the impaired body also contributes to this situation. For example, Morris (1991) has argued

*'...there is a tendency for the social model to deny the experience of our bodies, insisting that our physical difficulties are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability...to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, or fear of dying' (10).*

The reference to denying personal experience is part of Morris' challenge to the materialist positions on the place of subjective experience in disability politics. That position, articulated most clearly articulated by Finkelstein (1996), that exploring subjective experience distracts from political work of identifying social barriers which are external and exist independent of individuals. Second, Morris suggests that disabled people's experiences cannot be understood with reference to disability alone: impairment too has an influence. These points are both demonstrated in Morris' work which is usually rooted in first person accounts (see, for example, 1989 & 1991). However, Morris (2001) has also bemoaned the fact that disabled people are still loth to talk about their experiences of impairment for fear of non-disabled people turning around and saying, "there you are then, we always knew that your lives weren't worth living." (17). It is not clear what evidence Morris draws upon to argue that disabled people are loth to talk: does she refer just to those with a particular political understanding of disability and impairment or disabled people generally? This point aside, pertinent to my purpose is that Morris goes on to say that if disabled people

*'...don't confront what we need as a result of illness, pain, chronic conditions which inhibit our lives, then health services and support services will continue to be run in ways which disempower us' (21)*

So what is it that stops disabled people confronting what is needed by talking about their impairment? Morris indicates three related issues. First, she says the reluctance to talk is because impairment cannot easily be distinguished from disability. But why is it necessary to be able to separate disability and impairment before talking about the latter? This question can be answered by Thomas' (1999) observation that Morris assigns impairment to the private sphere and so talking about

it won't undermine the political project of barrier removal. But what of those who don't or can't separate their experiences of disability and impairment, what stops them talking? The second barrier to talking about impairment is that it would involve drawing upon and reinforcing negative cultural and medical views about impairment. Morris is not alone in this view (see also, Finkelstein, 2001a, Marris, 1996). In addition Linton (1998) makes the point that there is no neutral language available to describe impairment. But by the same token, it is only when people feel sufficiently empowered and supported to talk about impairment that such a language will be developed.

The final barrier to impairment talk is the difficulty of addressing the actual experiences of impaired bodies. For Morris, the source of this difficulty is the fear that addressing those experiences detracts from the political project. However, I think this difficulty is also conceptual: there is still much to do to capture what role disability and impairment play in 'the actual experiences of the body'. For example, is impairment ever 'simply' an integral part of bodily experience or at times does it feel like a bounded entity within the body? Nonetheless Morris' work has highlighted that without insight into impairment, it is difficult for Disability Studies to engage with health and illness issues.

To go back to the disability/impairment dichotomy, French's work (1993, 1999a) calls for the inclusion of impairment related issues in the social model. However, her basis for doing so is that not all social barriers can be removed by social change. To illustrate this point, French analyses her experience of moving into a new neighbourhood. Being visually impaired, French explained to her new neighbours that she would be unable to recognise and greet them in the street. Having explained this, at first neighbours took the initiative and identified themselves whenever they met her but after a while this stopped. French concluded that this difficulty is

*'...not entirely due to my impairment for it involves other people's responses but neither is it easily modified by social or environmental manipulation: it occupies a middle ground' (18).*

This 'middle ground' points to the importance of naming social interaction as one of the key sites of disabling barriers, for it is through interaction that most of the

business and pleasure of life is done. As Watson (2003) points out, it is through interaction that we experience the sociological abstractions of social structures, relationships and processes. It can also be argued that it is through interaction that we come to learn how others interpret our bodies, and this in turn influences the experience of health and illness (see chapter two).

### *Phenomenological Challenges*

Paterson & Hughes (1999) provide another way of analysing social interaction between disabled and non-disabled people. Drawing upon both phenomenology and post structuralism, they argue that there are embodied carnal norms of communication which structure social encounters with strangers. These norms are predicated on the functioning of non-disabled bodies. Applied to the scenario described above, French's initial discussion with neighbours can be construed as an attempt to disrupt norms of conversation. This disruption was short lived as the neighbours quickly slipped back into using non-disabled embodied norms. Paterson & Hughes' analysis of embodied norms shifts attention from the impaired body and the somewhat nebulous concept of social attitudes to the underlying structures which govern everyday communication. This is a reminder of the significance of the non-impaired body and how its ways and modes of function are interwoven into social structure and interaction.

Moreover, Paterson & Hughes also pay attention to the way disability and impairment interact and how *both* are embodied. They do this by using Leder's (1990) concept of dys-appearance. In everyday life, Leder argues, we are unaware of our bodies, we take for granted that our bodies have to act to enable us to be in the world. However, circumstances can arise where one does become conscious of one's body or certain aspects of it: hence the 'body appears as a thematic focus of attention, but precisely in a dys-state' (Leder, quoted in Paterson & Hughes, 1999:602). The prefix 'dys' here is both from the Greek meaning 'bad', 'ill' *and* from the Latin meaning 'away, apart or asunder' (Leder, 1990:84-7). So bodily dys-appearance can occur when there is something 'wrong' or 'bad' going on in one's body, for example pain or illness. In this state the body demands attention and in doing so may be experienced as something alien, away from the normal state of

bodily being. Applying this to disability, Paterson & Hughes (1999) argue that one of the circumstances in which impaired bodies dys-appear is when they confront disabling barriers:

*'When one is confronted by social and physical inaccessibility one is simultaneously confronted by oneself: the external and internal collide in a moment of simultaneous recognition... The impaired body ...is stunned into its own recognition by its presence-as-alien-being-in the world.'* (603).

I take this to mean that the experience of moments of disability is embodied; the external world is experienced internally. At the same time there is recognition that the environment is designed in a way which excludes and disregards one's impaired body. Paterson & Hughes stress that in the case of impairment and disability, dys-appearance is not a biological phenomenon but a social one. It is through engagement with the social world that one becomes aware of having a different, impaired body. For Hughes & Paterson then, impairment isn't a precondition of disability; rather awareness of impairment emerges through experiencing disability. So while impairment may be a quality of embodiment, it is not always nor continuously experienced. The value of Paterson & Hughes work is that it offers a way of describing the embodiment of impairment which is intimately and always experienced in relation to other people and/or the environment. Hence, as Paterson & Hughes point out, disability becomes impairment and vice versa. The dichotomy is smashed.

### ***Impairment and Psycho-Emotional Effects***

Using a very different approach to Hughes & Paterson, disabled feminist Carol Thomas (1999, 2004, 2007) also considers how disabled people's lived experiences 'are shaped fundamentally by the interaction of disability and impairment effects' (1999:125). To accommodate this within the social model, she makes two theoretical moves. First, she revisits the UPIAS definition (see above), and reinterprets disability as a social relationship between impaired and non impaired people within which restrictions of activity are imposed upon the former by the latter. Hence:

*'Disability becomes a particular form of unequal social relationship which manifests itself through exclusionary and oppressive practices - disablism - at the interpersonal, organisational, cultural and socio structural levels in particular social contexts.'* (40).

What Thomas doesn't say is why or how this unequal relationship arises and what role, if any, impairment or the body, plays in generating it. Nonetheless by interpreting disability as a relationship, Thomas provides scope for exploring disabled people's agency, particularly how they handle and resist disabling encounters. Thomas (1997, 2001) has also used this approach to explore empirically the disablism in the relationship between disability, women and healthcare professionals. So one way of explore disability and use of health services is to conceived of disability which influences social practices due to an unequal social relationship.

Thomas (1999) has also developed the concept of 'psycho-emotional effects' to alert us to the affect of disability on one's subjectivity and identity, making the point that social barriers do not only affect what disabled people are able to do but also who disabled people can be. Perhaps, however, the concept should be renamed 'psycho-emotional dimensions' to recognize that there is an emotional component not just as an outcome of disabling encounters, but also to the handling of access problems. In other words the emotional dimension is not just an effect but also can influence the encounter itself.

Thomas goes on to make a second theoretical move which is of most interest here. Having defined disability as the imposition of restrictions, Thomas argues that this does not preclude conceptualising impairment as *also* imposing restrictions. Thus she expands the social model to include impairment related restrictions which she dubs "impairment effects". Such effects, Thomas suggests, include pain, fatigue and her situation of being unable to grip a saucepan or spoon in one hand. What is shown is how easily impairment effects slide into disability. So, with the example of not being able to hold a kitchen implement in a conventional way, it is noted this could become a disability if it were used as a marker for disability: for instance, if the authorities used it to decide she was an unfit mother.

In her early work Thomas (for example, 1999) does little to draw out the interaction of the social and the biological which, she argues, shapes impairment effects. Essentially, impairment effects become a residual category for all the restrictions that cannot be understood with reference to disability. Moreover, in effect, Thomas' equates the social with disability and the biological with impairment, so fails to consider how the biological may be socially mediated. Hence N. Watson (2000) argued that the concept of impairment effects fails to present 'an analysis that embodies the experience of disability/impairment'. This, Watson goes on, can only be provided by 'the inclusion of the phenomenological experiences of living with an impairment' (56), something which is also called for by disabled feminist Wendell (2003). I would argue that it is only by doing this that we can get to grips with the nature of disability and impairment in terms of bodily and emotional sensations and capture how these are played out in lived experience.

Thomas' later work (2007) does acknowledge that being one-handed is a bodily experience and goes on to consider the complex ways that the social and biological interact. Again, using the example of being one-handed, she shows this is at once biologically and socially contingent: in the West there is a cultural expectation that in domestic situations 'pouring boiling water from an electric kettle into hand held domestic containers is an everyday activity' which requires two (steady) hands. Similarly, in a capitalist society, a missing hand is constructed by medicine as abnormality and this 'carries tremendous weight' (137). This begins to demonstrate the socially and culturally influenced ways in which bodies are interpreted and evaluated. However, it is difficult to know whether Thomas' examples are describing impairment affects, disability or, perhaps more promisingly, what she dubs as the 'bio-social phenomena' of impairment (137). This moves Thomas a step closer to abandoning the disability/impairment dichotomy because, if impairment is bio-social, isn't it the same as disability? However, to do this Thomas would need to let go of her materialist framework which posits that the barriers are still "out there" even while exploring the way they influence and are influenced by the body and emotions.

### *A Continuum between Impaired and Non-Impaired Embodiment*

If Thomas sought to expand the social model to take account of impairment, Shakespeare & Watson (2001) aim to do the same by moving away from the model altogether. Their starting point is that the split between impairment and disability is unsustainable because it fails to capture the lived experience of disabled people. The social model, they argue, has led to ‘the denial of difference’ between impaired and non impaired people (14). As a result there is scant recognition that ‘the different major groupings of impairment, because of their functional and presentational impacts, have differing individual and social implications’ (15). So recognising the salience of impairment is also a process of recognising the differences between disabled people. These arise from the complexity of impairment and the social relations which surround it. While Shakespeare & Watson make clear that they are not arguing for the disaggregating of the disability category nor for ‘referring solely to clinical diagnoses’ (15), it is not clear what conceptual tools they would use. While it is true policies and practices aimed at barrier removal often overlook the needs of particular groups - that is they fail to take on the range and complexity of impairment – it is also the case that the use of the over-arching term “disability” does provide some leverage for excluded groups to claim entitlement. De Wolfe (2002) illustrates this by acknowledging that, without the success of the disability movement, her struggle to get the doors of her library made accessible would not have been successful. Thus the challenge will always be to find ways to make claims for barrier removal that embrace most people’s needs whilst putting structures in place to enable people to respond to individual and particular needs (see chapter seven).

Shakespeare & Watson also highlight the fact that overlooking the impairment related differences amongst disabled people contributes to the disability movement’s antagonistic attitude towards both maximising functional abilities and medical attempts to cure impairment. Shakespeare (2006) develops this point in a later work, arguing that the disability movement overlooks the diversity and complexity of people’s impairment experiences and their life situation. Yet these factors influence people’s inclinations for or against impairment related medical interventions.

However, Shakespeare does acknowledge that part of the movement's objections stem from the media hype surrounding cutting edge curative treatments and from healthcare professionals who downplay the risks and limitations of such treatments. This line of argument highlights further reasons why Disability Studies has avoided engaging with health issues. Even where the effects of impairment are recognised, there is no theoretical space to consider the experience of impairment related bodily sensations or what disabled people have to do in order to live through an impaired body in a disabling world.

A further argument that Shakespeare & Watson make to break the impairment/disability dichotomy is that it is often impossible to see where impairment ends and disability begins. It is possible to identify three strands of this argument. The first is that some dimensions of disabled people's experiences involve the interaction of impairment, disability *and* something else beside. To make this point, Shakespeare & Watson draw upon the work of Corker & French (1998). The latter argue that pain is a feature of many impairments but that pain itself is not 'the sole creation of our anatomy and physiology' but emerges at 'the intersection of bodies, minds and cultures' (Morris, quoted in Corker & French, 1998:6). So pain can be a unique and added dimension of disability/impairment. Of course, the experience of pain is not unique to disabled people (Swain & French, 2000) so there is overlap between the health and illness experiences of impaired and non impaired people (see chapter two). A further dimension becomes apparent in the 'huge difference' between 'a Deaf person who uses sign language and/or has 'deaf speech' and a deaf person who uses hearing aids and communicates well orally' (5). Here, the impairment may or may not differ by degree but the disabling barriers encountered will be mediated by biographical and cultural characteristics such as the age of onset of deafness, the availability and desirability of medical treatment such as cochlear implants and whether other family members are deaf or use sign language.

The second strand of the argument that disability and impairment are not dichotomous is that the two continually interact so 'disability may itself create impairment' (Shakespeare & Watson, 2001:18) as well as impairment leading to disability. This can be illustrated using an aspect of my own experience: the effect of



disability in the form of inaccessible toilets and insufficient help to use the toilet over a sustained period has led to additional impairment, incontinence, which is not usually associated with my condition. Thus disability imprints itself on the body which then gives rise to new impairment effects and new forms of disability. This is expressed by the post structuralists Shildrick & Price (1998) who argue that social categories such as impairment and indeed the binary between impaired and non impaired people are fluid, 'always provisional and insecure, never entirely distinct' (236).

This prefigures Shakespeare & Watson's third challenge to the impairment / disability dichotomy, that impairment is always social and interpreted from a particular point of view. Impairment is neither (just) biological nor experienced pre-culturally. It 'is only ever viewed through the lens of disabling social relations' (18). Hence identifying and categorising a body state as impairment depends upon cultural interpretations which are contested and change over time. From this, Shakespeare & Watson conclude 'that there is no qualitative difference between disabled people and non-disabled people, because *we are all impaired*' (24, italics in original). This, the authors argue, is not the facile argument that 'we are all impaired really' but an empirical observation that we are all vulnerable to bodily limitations especially, but not only, as we age. Thus there is a continuum not (just) between impairment and disability but between impaired and non impaired embodiment on which all human beings are placed. Disability then marks off the point where 'people experience the additional disabling processes of society' (25).

Shakespeare & Watson's analysis offers my work two key insights. First they make it possible to reclaim the impaired body (and perhaps other bodies) from its dominant biomedical interpretations through their insight that the body is never viewed from a neutral or objective position. Other more positive interpretations of the impaired body are always possible and indeed are already being made especially in the context of Disability Arts (Swain & French, 2000). The second insight that Shakespeare & Watson provide me with is that impairment is always embodied. This opens up the possibility of exploring how disabled people experience their bodies in everyday life

and how these experiences are influenced by internal feelings and sensations as well as by external factors such as disabling barriers and social structures.

### *Post Modernist Challenges*

A further challenge to the impairment/disability dichotomy comes from those writing from a post modern and post structuralist perspective who regard the social model as ‘fundamentally flawed because of its association with a Marxist “meta-historical narrative”’ (Thomas, 2006:23). One example of such a perspective is the work of Tremain (2002). She argues that the division between impairment and disability is a ‘chimera’ because it is only people with impairments that can experience disability (42). In other words disability and impairment describe the same social phenomenon. Therefore the ‘strict division’ proposed by the social model fails and the categories of disability and impairment cannot be regarded as mutually exclusive as the social model suggests. Tremain then links this to Foucault’s argument that ‘modern relations of power produce subjects... who “have” impairments because this identity meets certain requirements of contemporary political arrangements’ (42). What these requirements are isn’t specified. From this view, impairments ‘must no longer be theorized as essential, biological characteristics of a “real” body’ (42) rather they are the *effects* of biopower and the outcome of discourse. Impairment is ‘naturalised’ to camouflage this.

But *what* is the outcome of discourse? Is it the phenomenological experience of impairment? Or the way that experience is socially constructed through discourse and practice? Or both? Let’s think about this through a mundane example, of me being unable to lift a mug a coffee to my mouth without spillage. First we need to know that Tremain argues that the ‘materiality of the body ought to be contested because the way bodies are discussed and interpreted are never “merely descriptive” but are also prescriptive’ (34). Shildrick & Price (1996) adopt a similar position when they dismiss the biological body in favour of the body which is constructed through discourse. So my inability to lift a coffee mug becomes notable because discourse creates the knowledge that most people can lift a mug and drink without spillage, and indeed can drink without awareness of the physical manoeuvres necessary for drinking. Hence straws are not always available in social spaces where

drinking from cups occurs, so sometimes I may go thirsty or risk spillage. And if I risk it, I may feel embarrassment because, again through discourse, I have been made a subject which regards coffee spilling as wrong, even infantile.

Yet Tremain's argument is that things could be constructed otherwise. It is just about possible to imagine a society in which straws are always available, or better still, are an integral part of the design of all cups. In such a society I would never go thirsty or be embarrassed when drinking. But where does all this leave the phenomenological experience of not being able to lift a cup and all the other things that are made difficult, impossible or simply messy due to unsteady hand movement? Shildrick & Price argue that saying the body is constructed does not imply 'that the *matter* of the body has no reality' just that 'there is no *direct* access to the unmediated body prior to discourse' (italics in original, 98). So we can only know and speak about the body through language and that language is constrained by what Foucault terms biopower, that is the knowledge and power of biomedical practice that shapes what is known about the body and who knows it. Again let's go back to the coffee. It *is* difficult to think about describing what my arm does without resort to the value laden medical language: "movement disorder" "dystonic", "lack of control". But on a bad day, I do know what it *feels* like to go to grasp something but I can't steady my hand enough to do so. Even if I had a mug with an integral straw I may still knock it over. I may not feel embarrassed because that is socially constructed and therefore can be deconstructed – but I'm still left with a mess to clear. (But do I say that because I'm a woman and gendered discourses constrain my thoughts about domestic roles?)

As I see it, the arguments of Tremain and Shildrick & Price do create the possibility that what are currently understood as impaired bodies which are devalued, could be perceived and treated differently. They also go beyond the radical intentions of the social model which sets its sights on removal of all social barriers but has nothing to say about impairment. However, there are three issues that appear to be missing in their arguments. First, it is not clear how the potential of viewing bodies differently is to be realised. Second, Tremain does not appear to allow theoretical space to explore the phenomenological body. Third, it is not clear whether disabling barriers

would persist even if impaired bodies were not objectified and were undifferentiated from 'non-impaired' bodies. On this point Tremain (2005) argues that the creation of the impaired subject provides the justification for the regulatory effects of practices designed to govern impaired bodies. This can be recast in terms of the relationship between impairment and disability; 'the category of impairment...persists in order to legitimise the governmental practices that generated it in the first place' (11). In other words, there has to be a social category of impairment to justify the regulation of the impaired body. If impaired bodies were left undifferentiated from non impaired bodies then the former could not be socially controlled.

### ***Impairment as Ambiguity***

The discussion so far indicates that much progress has been made in generating conceptual and theoretical tools to understand impairment. However, the nature of impairment as a social phenomena and an embodied entity is still not quite clear. It will become more so if we draw out one of the implicit themes in the above: the role of culture in shaping dominant images of impairment and the values attached to it. This will also provide a means of exploring the boundaries between impairment, illness and health, one of the objectives of this thesis. I will argue that the boundaries between these bodily states are fluid and indistinct and this is another reason why Disability Studies' scholars have been reluctant to engage with health issues.

### ***Cultural Values***

Those adopting a materialist understanding of disability and impairment have been criticised for paying scant attention to the role of cultural processes in the creation of disability (Shakespeare, 1994). Yet for Finkelstein (1980, 2001), who is considered a materialist, it is culture which provides the causal link between disability and impairment. Schematically asserting that the specifics of any culture and its normative assumptions emerge from the mode of production, Finkelstein argues that the attribution of a negative value to impairment is a wholly cultural process. So, using the example of missing an eye or an arm, he argues that there is nothing

intrinsically negative or limiting about this. That such missing body parts might be experienced as a source of personal grief is a product of a capitalist society. What's more, Finkelstein argues, it is due to the negative valuing of impairments that disabling barriers are erected<sup>1</sup>. Such barriers are a way of reinforcing norms of bodily capability and policing those who do not conform. The implication here is that all forms of bodily states - from being the fastest long distance runner to being a wheelchair user or deaf – are interchangeable if, through culture, they are imputed with equal value and society is organised in such a way that the needs of all bodily states are met. Yet it is difficult to imagine such a culture but this may be the problem Finkelstein is getting at: we are all so steeped in culture that we cannot imagine different ways of being.

Abberley (1997) develops the argument that impairment can be problematic. As a materialist he advocates an 'attitude of ambivalence' towards impairment, defining ambivalence as the 'co-existence in one person of love and hate towards the same object' (165). What he is suggesting is that impairment itself is a problem and should be prevented if possible. At the same time those with impairments should be respected. However, despite the definition of ambivalence that Abberley gives, what is not clear is how one separates impairment from the rest of the self so the former is hated and the latter is loved. This leads to an interesting question about the relation between self, impairment and embodiment. In other words is impairment a bounded entity within the embodied self? This is, of course, how most within Disability Studies (including myself) talk about impairment, as something we have or possess as implied by saying 'I have an impairment'. Crow (1992) argues that we need to 'find a way to integrate them [i.e. impairments] into our whole experience and identity' (4). The pertinent issue here has less to do with how this is achieved and more to do with why we conceive of impairment as separate from self. As we shall see in chapter two, medical sociologists make a similar argument to Abberley. They suggest that people with chronic illness objectify their bodies so as to cast the self as

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<sup>1</sup> Is there a circular argument here? Culture emerges from the mode of production from which disabling barriers emerge but the pretext for the imposition of those barriers is cultural.

the victim of the body and avoid the self being overwhelmed by it (Bury, 1982, S.J.Williams, 1996).

More promisingly for my purpose is Abberley's (1997) analysis of the social production of impairments through the interaction between the body and the socio-economic context, for example through industrial accidents or the prescribing of unsafe drugs such as Thalidomide. While not all impairments are created in this way (Shakespeare & Watson, 2001), this is the beginning of an argument that impairment is never exclusively biological and identifies the body in a social and economic context as the focus of analytic attention, although not at the level of everyday life. Abberley develops this by going on to argue that the effects of all impairments are always experienced through, and therefore influenced by, the particular social relations existing at any moment of time. A similar point, but with a greater degree of specificity, is implied by Crow (1992). Her argument is that some of the time impairment is 'irrelevant, neutral or positive' and at other time it is experienced as 'pain, fatigue and depression' (2). This suggests that whether impairment is a problem or not depends on the context, time and place and on how the individual evaluates his/her bodily state. So, although Crow sees impairment in essentialist, biomedical terms (Thomas, 1999) she nonetheless describes the experience of it as socially contingent.

Abberley takes his argument about the social production of impairment one step further by suggesting that 'for disabled people the body is the site of oppression, both in form and what is done to it' (73). Drawing upon the work of Sutherland (1981), Abberley identifies normalising medical treatment as one strand of oppression which is done to the impaired body: the example given is that of a person with polio who is made to walk using unwieldy equipment, despite the fact that is painful to do so. This is one area where Disability Studies scholars have engaged with medical issues and will be explored further in chapter four.

### *Impairment Is Not Neutral*

Recently Shakespeare (2006) seems to have shifted from his view explored above that the disability/impairment dichotomy is unsustainable. Rather he has argued that

impairment is a ‘problematic reality of biological limitation’ (40) which is ‘limiting or difficult, not neutral’ (46). From this stance Shakespeare argues that disabled people are restricted *both* by their bodies and by disabling barriers. Although Shakespeare evokes biology, in an earlier part of his book he makes clear that impairment is always social because impairment can only ever be experienced in society. Presumably, by the same token, the biological is always socially mediated. Shakespeare’s argument here seems to differ from that of Finkelstein, Abberley or Thomas’ concept of impairment effects on only two points. First, he is more forthright in the language he uses to capture the negativity of impairment and doesn’t see ambiguity where the others do. Hence he underlines impairment as an ‘explanatory relevance’ (42) in the understanding of disabled people’s lives. Also, Shakespeare debunks the idea that impairment is a ‘different but equal’ body state compared with non impaired people. This refutes Oliver’s (1993a) argument that a wheelchair is an equivalent mobility aid to a disabled person as an aeroplane is to a non-disabled person. What’s useful for my work is that Shakespeare suggests that regarding impairment as a limiting factor facilitates the exploration of what constitutes appropriate medical responses to impairment. Presumably this is because one criterion for evaluating the benefit of such treatment would be the degree to which it reduces the disadvantage that impairment causes for a particular individual, rather than considering the degree to which it is normalising (see chapter four).

The second difference between Abberley, Finkelstein and Thomas and Shakespeare is that Shakespeare is more pessimistic – some may say realistic – about what can be achieved by social change. In being so, he challenges the implication of the social model that all barriers could be removed to create a non disabling world. For example, he points out that many aspects of the natural world cannot be made accessible and that there are a range of impairment needs which cannot be accommodated through barrier removal. Further what Shakespeare hints at but doesn’t develop is how, when encountering an access barrier, a person may negotiate with others to mitigate its effects (see chapter seven).

## *Impairment in Others*

There is one further set of arguments that can be used to consider the nature of impairment: that concerning the attitudes of disabled people towards other disabled people. Morris (1991) points out that sometimes disabled people are

*'guilty of undermining the lives of [other] disabled people. Those of us who walk with crutches often think that to have to use a wheelchair would mean life would not be worth living, and those who do use a wheelchair but have the use of their arms and hands think that to be completely paralysed would be sufficient to commit suicide.'*(58)

Morris doesn't consider what lay behind these sentiments beyond noting that nobody can know for sure how they would live with an impairment which they haven't yet experienced. Through his empirical work on impairment, disablement and identity, N. Watson (2000) develops this point. A number of his research participants felt their 'own impairments were more tolerable, less debilitating than others'. So while two participants felt that their impairment, Multiple Sclerosis (MS), was preferable to being a wheelchair user, a third participant, a wheelchair user, thought having MS would be 'dreadful' compared with her situation (113/4). The explanation that Watson offers for this is that people become accustomed to managing their own impairment while 'unable to comprehend how others manage their own' condition (114). He goes on to highlight that a disabled person is subject to the same social and cultural norms as a non-disabled person and this informs how they view other disabled people. Yet when it comes to their own life, these norms are challenged by the detail of their own day to day experience.

Watson's argument implies that to understand what impairment is, it is necessary to understand the embodied self in everyday life. It is here that impairment (and indeed disability, if in fact the two can be distinguished) will become an explanatory factor – or not – and presumably will take many forms. This notion of impairment stands opposed to those above where the impairment is a bounded entity within the embodied self or the impaired body is divorced from the materiality and social relations in which it is enmeshed. Watson's argument can also be extended to give a partial explanation of the attitudes of non-disabled people towards disabled people. Recalling the argument above about the body being taken-for-granted in everyday



life, perhaps non-disabled people imagine that disabled people will be constantly reminded of their body, its pain and limitations, as they themselves would be if they were ill (Toombs, 1992). However, Watson's research refutes this:

*'when the body was present, this presence seems to be no different for many of the informants from that of other [non-disabled] accounts of health and illness, or of the body in everyday life' (121).*

In this section I have begun to look at the role culture may play in shaping the experience of bodily states which constitute impairment and the values the self and others impute to the impaired body. This has exposed a tension between celebrating the impaired body for its difference and diversity while also acknowledging that the experiences of the impaired body can be negative and limiting. The challenge that has emerged is how to hold and explore this tension in such a way that doesn't further devalue the lives of disabled people or scupper barrier removal through social change. Yet despite this focus on impairment, the bodily experiencing of it is still underdeveloped, although Watson begins to offer a way forward with this.

In the final section of this chapter, I want to explore the boundaries between impairment and illness. This provides another form of insight into the complexity and nature of impairment. I will argue that the fact that boundaries between these bodily states are fluid and indistinct adds another layer to Disability Studies' reluctance to engage with health issues. Doing this may seem perverse given the arguments above that disability and (for the most part) impairment are social issues - not medical - and establishing this has been vital. However these arguments also risk excluding some from the remit of Disability Studies or the broader movement, for example those 'disabled people whose bodies are highly medicalised because of their suffering, their deteriorating health, or the threat of death' (Wendell, 2001:18). It may also alienate this group from the disability movement (Shakespeare & Watson, 2001). Should understandings of disability shift so as to include this group of disabled people, and if so, in what way? There is also a further, unrelated question here: how is illness implicated in impairment and vice versa.

### ***Mapping the Boundaries between Illness & Impairment***

To begin mapping the boundaries between impairment and illness, I will review two relatively recent attempts to do this within Disability Studies (Wendell, 2001, De Wolfe, 2002). I will then consider how these boundaries can also be discerned in other concepts of illness found in the Medical Sociology literature.

Wendell (2001) tries to distinguish between impairment and chronic illness by using the categories 'healthy' and 'unhealthy' disabled people. The former are those with stable conditions whereas the latter are those with chronic illness. But pinning unhealthy on to the chronic illness category appears to simply shift the definitional problem to the undefined 'unhealthy'. Further using the criterion of 'stable impairments' to define healthy disabled people also runs into problems. This is because conditions such as spinal injury, polio or cerebral palsy which are sometimes considered stable are often not so due to vulnerability to both impairment and non impairment related infection or complications and the acceleration of the normal ageing process due to unusual wear and tear on muscles and joints.

Wendell then tries to shore up the unhealthy and healthy boundary by suggesting that unhealthy disabled people do not fit within the dominant social categories used to designate legitimate social roles for those experiencing particular bodily states. So in the context of illness, those with chronic illnesses are not given the 'time out' of social responsibilities afforded to the acutely ill, but neither are they well enough to return to normal life as can be the case for some disabled people. Similarly those with chronic illness are young enough to be expected to be economically active and yet unable to rest legitimately in the way that older people with chronic illness are able to do. In the context of disability, those with chronic illness often 'don't appear' disabled, or disabled enough, so have to continually voice and justify their needs in an effort to be included.

This leads Wendell to collapse the unhealthy disabled category into that of non visible chronic illness. For this group, Wendell argues, a major problem is lack of recognition as "genuinely disabled," instead being held responsible or blameworthy for their condition (29). Thus the issue seems to become the policing of the

boundaries between different types of illness and wellness. Individuals whose bodies don't, or don't appear, to fit existing categories are problematised by social relations. Individuals then have to work to make their bodies fit or deal with the consequences. What we see here then is not so much a difference between healthy and unhealthy disabled people, more that boundaries are social, contested and can have a profound effect on life opportunities.

The notion that those with chronic illness don't fit existing categories resonates with Murphy *et al's* (1988) understanding of liminality. The authors argue that disabled people exist in a liminal state, 'neither sick nor well, neither fully alive nor quite dead' (238) and hence in a 'socially ambivalent' position (235). As a result, disabled people somehow hover between the world of the healthy and that of the sick, 'nonpersons' having lost one identity but not yet formed a new one. This indeterminate social status, Murphy *et al* argue, extends to all areas of disabled people's lives, including being seen as asexual. They mainly attribute the liminal state to the social restrictions they see as inherent within impairment, along with the prejudiced and stigmatising attitudes towards disabled people. It is perhaps the case that Murphy *et al's* analysis is somewhat dated insofar as there is now greater recognition of the disability category and disabled peoples' political claims for a role in mainstream society. There is also a more general point to be made about instability of categories of body states. Research has repeatedly shown that people identified their bodily state as indeterminate, as existing between health and illness. Similarly it has been demonstrated that most people, most of the time have some minor illness symptoms such as infection or injury (Blaxter, 2004, Cornwell, 1984, Herzlich, 1973).

Wendell's next argument, and one De Wolfe also makes, is that the disability movement's antagonistic approach to medical cure and prevention of impairment is the proposition that disabled people's problems can be dealt with by social change. However, they argue that with some conditions the major problems emerge from the nature of impairment itself rather than from disabling barriers. This resonates with Shakespeare's argument considered above that impairment can cause biological disadvantages. Hence Wendell argues that extreme fatigue, which is a symptom of

her condition, is 'one of the most challenging impairments to accommodate' in society (25). But it is not clear that this is a fruitful line of argument on two grounds.

First, it is possible to think of many impairments that are equally as challenging to accommodate as chronic fatigue, for example someone with a physically stable condition who cannot communicate verbally, in writing or formal sign language. But the real point here is the sheer complexity of the relationship between bodily states of impairment and chronic illness on the one hand and how they are experienced when enmeshed in social relations on the other. Using the instance of any one impairment and the possibility of accommodating it as a basis for distinguishing between different categories of bodily states, is doomed. There can be no useful, objective ranking of conditions by their perceived severity because what is unbearable for one person may not be for another. Moreover, if any particular impairment can be accommodated is contingent on social relations and the way these interact with an individual's biography.

The second difficulty with Wendell and De Wolfe's argument that in some instances the problems people face are wholly impairment related, is that it is not clear what it achieves: if a problem is not disability related why amend the disability category to incorporate it? De Wolfe (2002) argues that disability theorists need to acknowledge the suffering of those whose conditions cannot be dealt with medically or socially. If this doesn't happen, she argues, those with chronic illness will be banished to the private sphere because social integration is contingent upon a lack of suffering. But this gets confusing when De Wolfe calls for illness rights, analogous to disability rights. Although such rights would still leave those with chronic illness in the private sphere at least now this would be socially sanctioned. So illness rights would legitimate social disengagement while disability rights facilitated active social participation. Despite this opposition it is likely that many disabled people would claim both sets of rights at different moments of their lives. Yet De Wolfe's arguments for illness rights seem to point not towards shared boundaries between impairment and illness but to the alliance of acute and chronic illness categories so as to extend the remit of the sick role.

As something of an aside to De Wolfe's arguments here, the dangers of connecting impairment or chronic illness with suffering is apparent in Cassell's (2004) often quoted text *The Nature of Suffering and The Goals of Medicine*. In the chapter on chronic illness, as well as freely using the dated term cripple, he argues that any attempt to facilitate the social engagement of people with chronic illness will itself cause suffering. He then, in effect, inverts the social model, arguing that while the social standards (barriers) which prevent disabled people participating in the social world appear to be external, in fact disabled people impose on themselves standards they cannot meet. It is very difficult to know what to make of this beyond its offensive patronage and lack of any attempt to substantiate its arguments by drawing on the experiences of those with chronic illness or the Disability Studies literature.

The work of Wendell and De Wolfe demonstrate the slippery boundaries between impairment, chronic illness and acute illness. Now I want to explore this boundary further by looking at different concepts of illness and the way impairment is implicated within them.

### *Illness as Undesirable*

Earlier we considered the normative negative values attached to impairment and attempts to challenge them. I now want to draw a parallel between these and the negative connotations associated with illness. There are no 'facts' or fixed definitions of illness (Turner, 1995). Rather illness is an evaluative concept used to identify and name body states deemed undesirable (Turner, 2004). This naming is underpinned by cultural judgements about what constitutes acceptable 'dysfunctions, pains or disfigurements' (Cassell, 2004:145) but these judgements and the categories they create are always contested and provisional (Herzlich, 1973). As we have seen, the same is true for impairment.

These difficulties in categorising bodily sensations have practical implications. For example, in the context of health and impairment, individuals (and their healthcare professionals) may find it difficult to distinguish between changes in bodily sensations that indicate an impairment related problem and those indicating the onset of illness unrelated to impairment. In this instance, impairment can overshadow

illness. Similarly, the difficulty of categorising bodily sensations and functions contrasts with the use of secure and water-tight categories used to establish entitlement or otherwise to support services and roles. Yet for all these difficulties created by social categories, it is hard to imagine how the social world would operate without them. One example of this is the difficulties people face when bodily sensations or functions suggest that something is wrong, but for whatever reason, this goes undiagnosed. Without a diagnosis, an individual's bodily experiences and the restrictions they cause are not legitimated, which can have a negative impact on relationships within the family and with employers. It can also exacerbate the existential anxiety which often accompanies the onset of illness symptoms (Bury, 1982).

Thus illness is a socially defined state which stands opposed to disease 'a neutral term referring to a disturbance in an organism' (Turner, 2004:198). While illness is clearly related to disease, the two are obviously not co-terminus: one can have a disturbance in the body without being ill and be ill without having a disturbance. In this equation, impairment has to be aligned with illness, as it too is constituted through social judgements of bodily states (Shakespeare, 2006). So on what grounds is illness and impairment deemed undesirable, what gives these concepts a normative basis? There are a number of answers to this.

First Crawford (1984) argues that bodily experience is 'structured through the symbolic category of health' (62). Therefore for most people in comparison with healthy embodiment, illness is at best unwelcome. Logic suggests that this should also apply to impairment: for those who have only experienced being healthy, the onset of impairment is unwelcome. So here it seems that impairment is implicated in illness. However, this cannot apply to those with congenital impairments who have no bodily experience without impairment, suggesting that the boundary between illness and impairment varies depending upon its onset. Further Sander, Donovan & Dieppe (2005) found that amongst older people the onset of impairment did not mark a significant discontinuity with previous body states because of their previous embodied experiences of poverty and hard work. But there is another confounding factor here, which is of greater significance. While the onset of impairment may be

compared unfavourably with a former healthy state, this comparison may not endure over time. This, of course, is the major difference between illness and impairment: the former has an endpoint of death or cure (Cassell, 2004) while impairment is by definition ongoing. By virtue of impairment being ongoing, to a greater or lesser degree people become accustomed to the bodily ways and sensations, so comparison with previous states may not apply. From this perspective the onset of impairment can be seen as an opportunity for self development (see for example, Albrecht & Devlieger, 1999, Frank, 1997, Lindsey, 1996). Against this interpretation, Swain & French (2000) point out that, in the minds of some, it is precisely the permanence of impairment that is the problem. From this stance, impairment is not the opposite of health but of death:

*'the ultimate version of the tragedy model is that physical death is better than the social death of disability' (571).*

The second line of argument used to demonstrate that illness is undesirable is that it impedes one or more bodily functions. In this regard Boorse (1975) makes the argument that categories of illness can be both descriptive and evaluative (he calls this weak normativism). To illustrate this with an example relevant to our discussion: claiming that walking is preferable to wheelchair use is not just normative. It is also a description of human functioning. In comparison with wheelchair use, walking improves circulation, keeps leg muscles toned and is a more effective and efficient way of movement over a variety of terrains. From this view, health is a matter of function, of the body working in the optimum way for everyday living. Against this impairment is dysfunctional.

Finally, there is an argument that illness is undesirable on the grounds that human beings prefer health to illness. This point is made by Canguilhem (1989) who states 'living beings prefer health to disease' (222). He goes on to suggest that this preference for health is not arbitrary but what is most 'conducive to life' for humans and an 'essential part of being an organism'. There is a risk here of 'biologization of norms' (Trnka, 2003:429) thereby neglecting the influence of culture in these matters. However, this biological determinism is avoided, Trnka argues, because

Canguilhem regards the preference for health as both subjective and ontological. It is subjective because

*‘experience of impediment and the subjective thought of an ideal are real as forms of sensibility and polarization in life. To be alive presupposes some ability to distinguish between good and bad in the sense of what helps or hinders me. This minimal sense of the evaluative is subjective for Canguilhem, meaning that it must take root in the individual organism’ (431).*

In other words, the preference for health is usually taken-for-granted but becomes apparent through the ‘experience of impediment’, that is when health is disrupted by illness, injury and so forth. This preference is also ontological because human beings have ‘evaluative dispositions’ (430), to choose health is part of what it is to be human. What is missing here is any discussion that a preference for health, or for what is conducive to life, is influenced by social and economic forces (although Canguilhem does discuss this in other contexts). There are two senses in which this is true. First, ‘what is conducive to life’ is dependent upon social and economic factors. For example, in a hunter-gathering society, being unable to walk would pose a far greater risk to survival than in a 21st century where wheelchairs are relatively sophisticated and the means of getting food relatively easy – at least in the Western world. Second, in the current age there are many different options that can be chosen which are ‘conducive to life’ including those which are accessible to disabled people. For example one can choose to keep fit by swimming, going to the gym etc and these do not necessarily exclude disabled people.

### ***Disruption of the Lived Body***

Another way of conceptualising illness is in terms of changes in bodily sensations or behaviour and our awareness and response to these. From this phenomenological perspective illness is conceived as a disruption to the lived body. Hence Toombs (1992) argues that usually the body is taken-for-granted and attention is focused upon the external world. In this state we live and perceive through the body without being conscious of it. This is the lived body. The onset of illness is marked by ‘alien sensations’ (14) and these cause our awareness to shift from the world and back to the body. From this point of view, it is relatively easy to distinguish illness from impairment. As Toombs (1992) argues, people become ‘acclimatised’ to the



impaired body so the sensations associated with it cease to be alien and do not cause attention to shift to the body. However, occasionally this may be problematic: a disabled person may have sensations which are only slightly different from normal, so ascribe them to impairment instead of to the early stages of an illness or change in impairment. Here then illness is implicated in impairment.

Toombs (1992) goes on to consider how changes in embodiment due to illness can change a person's perception and relationship to the external world. Drawing upon Merleau-Ponty, Toombs' starting point is that 'perception cannot be divorced from the concrete situation of the perceiver' (53). In other words, how perception operates through the body's five senses influences the interpretation of what is perceived. To illustrate this, Toombs uses the example of someone who has developed a tremor. If they see a mug of tea on the table, it is no longer simply on the table, 'there to be grasped'. Rather the mug presents itself as a problem to be solved (1992:11). Leder (1990) makes a similar point, arguing were he to 'become weakened or paralysed, the quality of the world is equivalently transformed: objects now recede, mock me, proclaim my inability' (23). Toombs goes on to argue that the bodily changes caused by illness or impairment result not just in a physiological loss but also a loss of personal integrity. The example given is that of someone becoming a wheelchair user losing integrity symbolically, because being upright refers not only to the physical act of standing but also metaphorically to having moral worth.

In some respects, the work of Toombs and Leder are useful insofar as they highlight how the relationship between embodiment and the external world. Hence Leder argues that our physiological structure is 'the groundwork of our mode of being-in-the-world' (quoted in S.J.Williams, 2006:10). This suggests that disabled people have a different ontology, a different way of being in the world. However, one problem is that, despite Toombs' acknowledgement of the differences between acute and chronic illness, she does not appear to take that into account in her analysis of the relationship between disabled people and the external world. To go back to Toombs' example of the mug, the person may use a straw - meaning that the mug is neither an object to be grasped nor a problem to be solved but a drinking receptacle in which to place a straw. In other words, unlike the social model, a

phenomenological analysis does not consider how an individual or social agent may intercede to change the relationship between the individual and the world of objects. This confirms a common criticism of phenomenology: that it is essentially individualistic and descriptive (Turner, 2004). It is for this reason that Hughes & Paterson's (1999) analysis, considered earlier, 'grafts' a phenomenological approach to 'notions of oppression and inclusion' (598).

### ***Illness as Social Action***

A third way of looking at illness is as a form of social action. Herzlich (1973) argues that we come to understand certain bodily states as illness through the meanings we assign to them. This happens through action or behaviour. For example if someone has a headache he may think it means he's tired so goes to bed. If the pain gets worse he may decide that the headache is more serious, so leave work and seek medical advice. Hence through social action (Herzlich, 1973), biology and culture interact to construct illness or impairment and the disease categories used to describe and manage these.

There are a number of issues that flow from this. The first of these is that illness can be understood as a change and restriction of activity: the serious and persistent headache means one is temporarily unable to work. As we saw above, both disability and impairment have also been defined as restriction of activity. Nonetheless, the point is that many disabled people manage to forge satisfying lifestyles, restrictions of activity notwithstanding and could do more so if disabling barriers were removed. Yet perhaps one of the reasons why non-disabled people are often incredulous that disabled people lead satisfying lives is that they base their judgements on their own experience or fear of restricted activity, suggesting that this is one of the ways illness implicates impairment.

The idea that disabled people incorporate restrictions of activity into their lifestyle feeds into the next issue that emerges from Herzlich's analysis, namely that there is an element of choice in how people act when they consider themselves as ill. So Herzlich (1973) goes on to argue that if one is ill but behaves as if one is well, then

one is healthy<sup>2</sup>. This argument seems to describe the approach of many disabled people to living with an impairment. As we saw above, the action one takes is influenced by the meaning assigned to one's illness, and these meanings are culturally shaped. This is also true of impairment but most of the meanings of impairment which are culturally available are 'uncompromisingly negative' (Pillsbury, 2001:55) and reinforce the personal tragedy theory of disability (Barnes & Mercer, 2003).

### **Conclusion**

In this chapter I have tried to highlight the aspects of thinking on disability and impairment which have impeded consideration of disabled people's health care encounters and of the relationship between the bodily experiences of impairment and disability on the one hand and health and illness on the other. Yet these impediments notwithstanding, in some senses Disability Studies' lack of engagement with health matters may be more apparent than real. Or rather it has explored these issues in a defensive rather than an engaged way. This I think is an indication of the seemingly high stakes involved especially in bioethical debates about beginning/end of life decisions and what has become to be regarded as normalising treatment. I intend to demonstrate all this in the three following chapters.

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<sup>2</sup> One could also argue that the reverse is also true: if one is healthy but acts as if ill then one is ill

## CHAPTER 2

### Impairment, Chronic Illness and Health

#### *Introduction*

This chapter will discuss the relationships between impairment, chronic illness and health. It will pick up one of the themes from the last chapter, the ambiguity which seems to be inherent in the concept of impairment. It will do this by contrasting arguments that the onset of impairment or chronic illness is negative with that which sees it as an opportunity and consider the reasons for this. It will then consider how impairment has been implicated in concepts of health. Particular attention will be paid to a line of argument that chronic illness or impairment is something that suggests attending to impairment and disability in everyday life is a form of work, of doing to the body. I will argue that this offers a way through and beyond the notion that impairment is either negative or positive and has the potential to contribute to new insights into the lived experience of impairment and disability. My underlying purpose here is to tease out the relations between health and impairment and consider why this relation is significant.

#### ***Chronic Illness as Negative: Disruption Repair and Reconstruction***

One focus of the chronic illness literature has been personal responses to such illness (Paterson, 2001). Hence one of its key concepts is biographical disruption.

Developed by Bury (1982), this posits that the onset of chronic illness disrupts ‘the structures of everyday life’ (169) at a number of different levels. One implication of this disruption is that those with chronic illness must rethink their biography because the ‘normal trajectory’ of one’s life becomes ‘fundamentally abnormal and inwardly damaging’ (1982:171). What is significant here is Bury doesn’t make the argument that life becomes ‘fundamentally abnormal’, but seems to simply assert it. To mitigate the effects of such a life, a person’s biography becomes a resource which can be used to assign meaning to their illness experience, to try and answer the ‘why me, why now’ existential questions illness can provoke. Bury makes clear that the informants were not seeking medical explanations for the cause of their illness but lay explanations, such as poor working conditions or stressful family situations. This

links with Cornwell's (1984) study of concepts of health and illness amongst East Londoners. In 'private accounts' of their illness which are given to those who the speaker knows, individuals look for multiple causal agents rooted in their experience. Here then, biographical disruption is the *source* of chronic illness (S.J.Williams, 2003) or biographically triggered (S.J.Williams, 2000), a concept that could be used to trace the relationships between social position, illness and biography. There is also a sense of biographical continuity. In searching one's personal history for explanations for current illness one's biography can to some extent counter the uncertainty of the present. This is what Carricaburu & Pierret (1995) call 'biographical reinforcement' (80). Similarly, although everyday life is disrupted, one remains 'the same person' before and after the onset of illness, as core identity doesn't change' (Kelly & Field, 1996).

Bury's ideas about repairing disruption by finding an explanation for illness is similar to G.Williams'(1982) concept of narrative reconstruction. This concept describes a process whereby the rupture of body, self and society that chronic illness may cause are accounted for and repaired through 'discursive consciousness' (178). This consciousness entails producing a commentary in everyday talk of the sequence of events surrounding the onset of chronic illness, particularly identifying reference points in their biography that they implicate in the genesis of their illness. The genesis of illness means not the disease aetiology but the social, biographical and teleological causes of the illness: that is the 'why me' question. This takes place within the context of their belief systems and it highlights an ordinary and everyday way of dealing with bodily disruption. It also indicates one of the ways in which the experience of chronic illness comes to be accommodated within the self and so offers the possibility of returning to a 'normal', if changed, lived experience.

There are a number of difficulties with Bury's concept of biographical disruption. The first of these is that his analysis focuses upon chronic illnesses which have a relatively slow onset. It is not clear if this is because biographical disruption is limited to this type of illness or whether it also occurs amongst those who experience a sudden onset of impairment, for example, as a result of a traumatic spinal or brain injury. Similarly, Bury doesn't consider the case of those with congenital

impairment. Obviously, amongst this latter group there is a continuity of biography and identity (assuming that the impairment isn't progressive, degenerative or episodic). Nonetheless, in comparison with non-disabled people, their lives may be disrupted in terms of the consequences of impairment upon daily living. This raises the question of whether to place the emphasis on the concept of biographical disruption on the disruption itself or on the content or form of that disruption takes.

This leads on to the second difficulty with biographical disruption, namely whether such disruption *always* occurs with the onset of chronic illness. Recent work suggests otherwise. For example, Sander, Donovan & Dieppe (2005) found that amongst older people, the onset of arthritis was an 'integral part of their biographies' as the condition was seen as 'an inevitable result of their [i.e. the respondent's] history and older age' (234/236). Notwithstanding this biographical continuity, the impact of the condition on daily lives was severe. This suggests that disruption to the lived body doesn't necessarily disrupt people's sense of who they are, doesn't necessarily divide life into 'before and after' illness. One explanation for this is that older people have a lifetime's experience of coping with adversity [and this] equips them to deal with illness cognitively and emotionally (S.J. Williams, 2000). If this is the case it suggests that disruption is linked to the ability to deal with consequences of illness in the routines of daily life: the greater the ability to cope, the less the disruption. It follows from this that the social contextual factors such as age, social history, expectations and personal resources are influential in determining the degree of biographical disruption brought about by chronic illness, rather than factors intrinsically linked to illness.

The third difficulty with Bury's concept of biographical disruption is that it assumes that such disruption only occurs in the context of chronic illness. This overlooks the disruptive effects of a number of other life events such as pregnancy, having children or death of a loved one. In doing so an opportunity is missed to highlight the similarities between illness and other life events. Arguably, this increases the sense of isolation, the sense of disconnection between those who are ill and those who are not. Similarly it fails to consider that a wide range of life experiences may equip people resources and skills to accommodate impairment or illness.

The final difficulty to be noted here is that when biographical disruption occurs, there is a presumption that it will always be a negative experience. In the context of the Medical Sociology literature generally, Thorne (1993) observes that chronic illness is assumed to be ‘traumatic’ for the whole family and the ‘inevitable outcomes of disease’ (33). Yet, she goes on to argue, the outcome is influenced hugely by the medical care available and the way in which it can be accessed. From a Disability Studies perspective, Sapey (2004) argues that a focus on meaning reconstruction rather than disruption may facilitate more positive practices on the part of healthcare professionals, enabling them ‘to work in collaboration and as allies to disabled people’ (25). He cites research by Oliver that suggests that there are a wide variety of responses to adverse life events, including the onset of impairment. Following Abberley, Sapey goes on to argue that any loss experienced by a newly disabled person may have as much to do with experiencing social barriers and disablism as with bodily disruption. . Again, this underlines the importance of tracing the social causes of disruption as well as the bodily ones.

A final point to note about this work on chronic illness is that it implies that the “disruptive body” is the trigger for biographical disruption. This stands opposed to the social model of disability, which, as we have seen, locates the problems of disability firmly in social structures and relations. From this perspective, impairment is not implicated in chronic illness, even though in common usage the meanings of impairment and chronic illness overlap and refer to similar body states. However, this can not be said with any certainty as there is no sense of the fleshy body here, making it harder to discern the nature of chronic illness.

### ***Illness as Opportunity***

The idea that biographical disruption is always a negative experience has been challenged by ‘a more optimistic view of illness experience as a form of self-development and liberation’ (Sander, Donovan & Dieppe, 2005:228). This is exemplified in the work of American sociologist, Arthur Frank (1995, 1997, 2002). Frank (2002, 2007) argues that illness provides a ‘dangerous opportunity’ to reflect upon and re-evaluate what’s *really* important in life. Serious illness forces people to confront the possibility of death. As a result, such illness becomes a moral occasion,

one which begs the question: what sort of person do I have to be in order to live with a less than satisfactory situation? When people engage with this question, they often recognise the possibilities of adopting valued and valuable lifestyles, notwithstanding illness. This is something that is not usually expected of those who are ill. Here the question of whether illness or impairment is a negative or positive experience gets pushed aside. Instead, Frank implies that through reflexivity, illness is an embodied state that offers a unique perspective on the world. Moreover, this perspective is socially valuable because it leads to consideration of how to live well. This also serves to decentre medicine from its usual position at the core of illness experience. As Frank points out, most of the life of someone with a chronic illness is lived outside the clinic. Here, impairment and illness again overlap, doing so when the possibility of death is faced.

### ***Impairment and Health***

In a similar vein as Frank, Lindsey (1996) uses the concept of health within illness to argue that the onset of chronic illness can be positive. This concept, developed by Moch (1998), posits that health and illness are not dichotomous, but each is a part of our existence to different degrees at different times of life. Lindsey's findings from a small scale, qualitative study demonstrated that people used the experience of illness as an opportunity to develop, enhance or refine their sense of Self. For example, interviewees spoke about deepening relationships with others, clarifying what was important in their lives, making positive life changes and finding new freedoms in their life. However, there are difficulties here. As Lindsey uses the concept, it infers that health within illness occurs only where there illness prompts self development. This doesn't seem to allow for other, equally positive, responses to illness such as disability related political activism. Yet that would risk seeing any positive activity undertaken by a disabled person as healthy rather than just pursued for its own sake.

A second difficulty with Lindsey's application of the health within illness concept is that it risks denying the very sense of embodiment which she sets out to consider. Lindsey argues that health within illness occurs 'regardless of the person's physical condition'. It is quite difficult to know what to make of this. Is she suggesting the idea of health within illness has no physical or phenomenological basis? How then



does health within illness differ from health? Perhaps this reading is too literal and what is meant is that illness, whatever its particular characteristics, can be an occasion for personal growth. But this interpretation again doesn't really provide a means of specifying whether disabled people's experiences or meanings of health are any different from those of people who become ill and then recover.

The third and final problem with the health within illness concept is it focuses upon an abstract individual, without reference to how the social context and biography impinges and shapes responses to illness and impairment. In other words, it is not clear what factors encourage or impede people to strive for health within illness.

To sum up, Lindsey's use of the concept of health within illness in the context of disability creates the much needed theoretical space to dismantle the usual opposition between health and illness or impairment. Such opposition is epitomised in Murphy *et al*'s (1998) assertion that 'a person who cannot walk and move about in a wheelchair can hardly be called "well"' (238). More generally, such opposition has also have been found in lay understandings of health and illness (Herzlich, 1973). However, as yet the health within illness concept doesn't seem sharp enough either to differentiate between the concepts of health, illness and impairment or to delineate the various situations where they can coexist.

In some senses, there are similarities between Lindsey's health within illness and what Albrecht & Devlieger (1999) call 'balance theory' 'where the experience of well-being and life satisfaction is contingent on the person's achieving balance between body, mind, and spirit' in the context of the larger environment (978). This theory was developed from analysis of research designed to investigate the apparent paradox that many disabled people 'report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence' (977). Whereas Lindsey identified self development as the key to a positive sense of health, Albrecht & Devlieger identified a number of outlooks on life which facilitated such a sense. These included 'just getting on with life', finding new ways to connect with others, finding new meaning to life through spirituality, weighing up different aspects of life and realising that the onset of

impairment was relatively unimportant'. These responses to impairment are not, Albrecht & Devlieger argue, about denying impairment but about acknowledging it and thus being in control of mind and body.

Herzlich (1973) discusses the relationship between concepts of health and illness used by lay people. She suggests that there are different bodily modes of experiencing health: as a state of well being, as a possession or as a means of conduct. Each mode is associated with a different concept of health and relationship between body and self. So, for example, the concept 'health as absence of illness' is experienced bodily either as 'being healthy' or 'being ill'. In other words it is a dichotomous state, one is either ill or healthy and one or other of these states pervades the whole experience of the body. Within this mode of being, it is relatively easy to imagine how the bodily experience of illness is very different than impairment. For example, having the flu is likely to be a very different bodily sensation than having cerebral palsy especially if a status quo has been established with the latter.

So those who have an ongoing, stable impairment would be likely to consider themselves healthy as this is their usual way of bodily being in the world. Thus health can combine with illness. A further mode that Herzlich identifies is equilibrium which is experienced through doing health, and knowing that the body is all right which facilitates participation in the world. It has similarities both with Lindsey's health within illness concept and Albrecht & Devlieger's balance theory.

### ***Being Healthy and Impaired***

Moving on, I now want to look at work which suggests that some disabled people view themselves as healthy, using similar or identical concepts of health to those used by non-disabled people. This is illustrated by Lowton & Cabe's (2003) qualitative study which investigated how people with Cystic Fibrosis (CF) viewed their health. For the purpose of the discussion here, it makes a number of significant points.

Despite CF being a highly medicalised condition requiring ongoing medical supervision, most of Lowton & Cabe's respondents regarded themselves as healthy. Just what they meant by being healthy was fluid and shifting, depending not (just) upon the disease process but on the social context and comparison with others. For example, one meaning given to healthy was being able to have a lifestyle comparable with those without CF. This meant being able to participate in everyday life by holding down a job or having a social life. This functional concept of health, the idea that being healthy means being able to cope with everyday activities, has been found in other [non-impairment] studies of lay views on health (Blaxter, 1990). Similarly, the technique of comparison with non-disabled people was also important to respondents in Albrecht & Devlieger's (1999) study of disabled people's evaluation of their quality of life – see above. In that context, for example, respondents used comparison to highlight that they gained life satisfaction in different but equally valid ways than non-disabled people or recognised that they had found a way of coping that meant they were able to have a better life than many non-disabled people.

Going back to Lowton & Cabe's findings, when respondents needed significant medical treatment, for example intravenous antibiotics to deal with a chest infection, most still regarded themselves as healthy. In this context however, health was a 'controllable state'. This meant that respondents still had control over everyday life by means of having a positive attitude towards having and managing CF. In this situation, health wasn't comparable to those without CF. Yet again the idea that health is a controllable state ties in with other lay concepts, particularly that good health is about 'overcoming disease, even if that disease is actually present' (Blaxter, 1990:16).

Lowton & Cabe interpret respondents' perceptions of being healthy as a strategy to manage their condition. This interpretation provides a useful insight into how seeing oneself as healthy is also a way of being healthy. It underlines the fact that having a positive attitude towards CF is an important part of dealing with it. As Lowton & Cabe point out, this does not mean that respondents were denying their health problems, rather by placing them in the larger picture of their own life and that of

others. However, this analysis can also be seen as problematic. It could be argued that by seeking an explanation of why people with CF viewed themselves as healthy, Lowton & Cabe failed to take respondents' health claims at face value. By making the fact that people with CF see themselves as healthy a significant finding, Lowton & Cabe collude with the expectation that those with highly medicalised conditions like CF are almost inevitably considered to be ill. This expectation was also held by four respondents who considered themselves to be 'frauds' precisely because they felt healthy and yet had a CF diagnosis. An indication of the strength of this expectation is that respondents seem to discount their experience, labelling themselves as fraudulent, rather than challenge the idea that someone with a medicalised condition cannot also be healthy.

### ***Disability as Work in the Context of Health***

In the previous section, I considered the similarities between disabled and non-disabled people's concepts of health. I now want to consider a body of literature which may seem to undercut these similarities.

It does so because it highlights the effort and additional tasks disabled people do to maintain health and manage activities of day to day living. The obvious place to start exploring this is with the Medical Sociology literature that looks at how people manage or cope with chronic illness or impairment. However, this is often descriptive rather than analytic, and does not always consider the broader social context. Therefore I want to start with Tighe's (2001) study of how impairment and disability impacted on the health of disabled women. This introduces the concept of disability as work, which I will argue could be developed to provide a useful vantage point from which to understand what it takes to be impaired, disabled and healthy

For most of the eight women Tighe interviewed, the need to keep up with or survive in a non-disabled world 'confounded the meaning of health' (519). In other words, women reported that their efforts to be healthy were compromised by having to deal with disabling barriers and attitudes on a daily basis. It is this need to deal with barriers that constitutes the first type of disability work. The second type of disability as work that Tighe highlights is what disabled people have to do with and

for their body in order to keep healthy. What this involves is contingent upon impairment and people's access to the personal, economic, social and medical resources which enable them (or not) to manage their conditions. This tallies with studies which consider how those with chronic illness cope with their symptoms on a day to day basis, and the impact this has on one's identity and sense of self (see, for example, Charmaz, 1983, Corbin, 1985 & Locker, (1993). However, one advantage of Tighe's concept over these is that it begins to include the social barriers that disabled people have to negotiate, *as well as* dealing with the body.

The third type of disability as work Tighe identifies is the pressure on disabled women to define and maintain the same level of health as non-disabled people. Rather than live life at their own pace to accommodate disability work, the disabled women in the study felt they had to do this work *in addition* to everything non-disabled people do in daily life. This disability work was physically and emotionally draining, which impacted negatively on their health. So not only did the women have to do additional work to be healthy but that work *itself* can be detrimental to health. Underpinning this double whammy are the social structures that fails to take account of disability work, which contributes to disabled people's discrimination and exclusion.

A final point Tighe makes is that how non-disabled people view the relationship between disability and health impacts on disabled people's perception of health. For example, one of Tighe's interviewees commented that while she viewed herself as healthy, she was aware that others saw her as 'fragile'. To confound this perception, the interviewee travelled 'all over the place'. When others expressed surprise about this, the interviewee felt she was 'changing those attitudes about disability and illness'. Tighe comments that the interviewee 'needed to exonerate her good health in light of her impairment' and thus 'The negative societal perception of disability impacts how [the interviewee] has to think about her own health'. Since acquiring a spinal injury, health has become something she has to strive for rather than health being something she could take-for-granted (520).

Zola's (1991) work provides insight into another dimension of the additional body work some disabled people have to do, one which focuses upon the relationship between embodiment and social space. He describes his changed perceptions of his body between two episodes of air travel. In the first, having parked the car in a convenient spot, with luggage strapped to his back he limped to 'what often seemed the most distant terminal in the airport'. When questioned about this experience of air travel, Zola replied that any problems were 'relatively minor or non-existent' (4). Twenty years later, in the second episode, Zola used a wheelchair to get from car to the air terminal. In doing so he *noticed* his body was

*'untired, not needing a nap, not sore from sweating legs and tight braces, not cramped from the general strain of extra walking' (4).*

From Zola's account here several related points can be made about impairment / disability work here. The first of these is the sheer effort involved in getting from A to B and the impact this had on his bodily being, an effort that a non-disabled person wouldn't have to make. Yet he only became aware of this effort and its bodily impact – his body only dys-appeared, to use Leder's terminology - when he avoided the effort by using the wheelchair.

This is an indication of how impairment becomes an integral and undifferentiated part of embodiment (Watson, 2000) to the extent that Zola didn't notice the effort he expended or how tired and sore his body used to get until he chose to stop walking and use a chair. The obvious point here is that the disability work, like the body itself, becomes taken-for-granted. This may in part account for what Zola described as his 'own inability to communicate the quality of experience' of walking being so effortful for him (4). Assuming this inability is not unique to Zola, it suggests the need to explore the extent to which this represents a barrier in understanding disability and its relationship with impairment.

The taken-for-grantedness of some disability work can have contradictory implications for the individual. If one is not aware of the work, it may make it easier to 'just get on and do things' which is what Zola did. Although he couldn't hide his

impaired body because of the manner and mode of his walking, he could make it appear as if it didn't impact on what he could do. In terms of functioning he could appear to be 'just like anyone else' (4). This may not have been Zola's intention or goal but the embodiment of prevailing culture and norms. The invisibility and silence of disability work colludes with the inadequacies of attempts to make appropriate adjustments to enable full participation in society. At the individual level, this can carry a personal toll in the form of bodily damage in the future. Indeed, it is now becoming apparent that people like Zola who had polio are now experiencing 'post polio syndrome'. One of the symptoms of this is painful or strained muscles which have been overworked or awkwardly used in a bid to compensate for paralysed muscles and an inaccessible environment. Similar problems are being experienced by people with other conditions, for example cerebral palsy. A suggestion can be made here that healthcare professionals are also implicated in taking for granted the effortful work of impairment by not considering its long term effects.

A final point to make about Zola's experience is that what changed between the two episodes was neither his impairment nor the physical environment of the airport. Rather what changed Zola's analysis of the situation was the growth of the feminist and disability rights movements. As a result of the new discourses these movements engendered, Zola's self perceptions changed. He no longer felt he had to prove he was 'just like anyone else...a "supercrip" (4). This suggests that political ideas can become embodied. The disability rights movement legitimated and valued diverse modes of bodily being and functioning and emphasised that society had to accommodate impaired bodies rather than vice versa. It was this that enabled Zola to make the choice to use his wheelchair rather than struggle to walk without diminishing his sense of self, without having to emulate non-disabled people's standards, without feeling the need to prove himself. This resulted in his body feeling much more comfortable – 'untired', 'not sore' etc. In this context, impairment becomes something quite different from illness. As Lupton (2006) observes society sanctions the temporary withdrawal of the sick person from her normal social roles and responsibilities while those with chronic illness are expected to adapt and be part of the world.

### *Adapting to Chronic Illness*

Moving on, some interesting comparisons can be made between Tighe's concept of disability as work and Bury's (1991, 1997) writing on adapting to chronic illness. Bury's focus is less on the doing of material tasks and more on the self processes necessary to facilitate such tasks (1991:460). Bury identifies three types of self processes: coping which involves integrating the consequences of illness into the lived body; strategising which involves mobilising the necessary resources for daily living; and style, 'the way people respond to, and present, important features of their illness or treatment regimes' (462). While ostensibly covering similar ground, the key difference between the approaches of the two authors is that while Bury is essentially normative, Tighe implicitly challenges the social status quo. The language that Bury uses, "adaptation", "coping" "putting up with" all speak of the individual doing all she can to 'achieve a level of normal life' (1997:129). Here, of course, 'normal life' is the life of non-disabled people. Without elaborating what normal life may be, or what sort of lifestyles people with chronic illness may aspire to and achieve, Bury's analysis risks making coping, strategising and style ends in themselves. This makes the burden of work all the heavier and it is small wonder that De Wolfe (2002) finds the Medical Sociology approach to chronic illness profoundly depressing and isolating.

It is interesting that Bury makes scant reference to health as if chronic illness rules it out of court. Yet for Tighe, by placing the concept disability as work in the context of health implies that this is the goal of such work. Tighe recognises that while many concepts of health are based around non-disabled people's standards and that these can be oppressive, these can also engender well-being and enable people to engage in the world. This was something that the women in Tighe's study worked towards. As we have seen, Tighe highlighted that dealing with disabling barriers was a significant part of disability as work, and this included dealing with the emotional consequences of dealing with prejudiced attitudes. This work could jeopardise health. Thus, in comparison with Bury's approach, Tighe's took greater account of the social constraints which the disabled women faced and engaged with through doing disability work.



There are several other examples of Medical Sociology studies on coping or adapting to chronic illness, and these too can be considered through the lens of disability as work. Kelly & Field (1996) argue that dealing with 'the physical problems which the chronic illness generates' is the 'epicentre of coping experience' and is secondary to attending to social relations and the reconstruction of self (247). What this argument overlooks is that dealing with social relations can be an integral part of managing the problems of illness or impairment. For example, managing the fatigue which is a major part of several chronic illnesses such as MS (Multiple Sclerosis) or CFS (Chronic Fatigue Syndrome), involves negotiating social relationships, both with significant others and those in the wider world, so as to manage demands upon one's time and expectations of social capacity. Similarly, both the self and identity are implicated in body management. How one attends to body management is, I would argue, both conditioned by and reflects the self. For example, the self may neglect body management: someone with a spinal injury may develop sores as a result of not checking pressure sites in the prescribed way. Consequently, healthcare professionals may attribute laziness or being neglectful to the person's identity.

Radley & Green (1987) and Radley (1989) also explore the notion of adjusting to chronic illness. Similar to Bury's notion of adaptation, this work can also be read through the lens of disability as work, throwing some interesting light on it. Everyone, disabled and non-disabled, does body work, which is not prior to everyday life but an integral part of it. From this point, Radley (1989) conceptualises adjustment as comprising the resolution of the 'dual demands of bodily existence and social life'. For disabled people, what has to be done to or with the impaired body - 'the demands of the bodily existence' - may dictate 'the terms in which the day shall be lived and personal relationships engaged in' (232). But the impaired body which has to be worked upon is the same body through which one experiences and engages with the social world. Therefore the desire or need to engage in the world is in competition with bodily demands for the same time, energy and resources of the individual.

Radley highlights that these conflicting demands should not be regarded as the simple opposition of social constraints associated with engaging in the world and the

physical constraints associated with body works. This is because social constraints are realised through the conduct of the body and body demands are 'defined and limited through social interpretations' (233). All these constraints are resolved through the process of adjustment, which is 'located in the practices and the discourse of the people concerned' (233). It is through discourse that individuals talk about what illness means and justify their way of coping with it. It is, therefore, a practice itself and its form constitutes part of their adjustment style. Adjustment is also done through bodily practices and the way these are used on a day to day basis. For example, one may choose to do an hour of physiotherapy or rest for the morning so one has the energy to go out in the afternoon. Hence, as with Tighe's concept of work, for Radley's adjustment is something that has to be done. It is a state of bodily doing rather than a state of being.

Radley goes on to argue that adjustment is not made to a fixed and nebulous concept of society, but to the specific social situation of the individual. So, for example, the adjustment to paid work after the onset of illness will involve very different issues for the lorry driver than for the accountant. Radley & Green (1987) also argue that there are different modes of adjustment which are shaped by the individual's relationship with his condition on the one hand and with society on the other. For my purposes, the important point is that adjustment is not a uniform process but varies both between individuals and with the same individual over time, depending upon how they negotiate social and bodily constraints.

### ***Body Management***

#### **Need discussion here about body management in general**

For some disabled people the nature of their impairment can be such that certain types of body management are always problematic. For example, Kelly (1992) found that although managing a colostomy was usually a background feature of life, if the appliance failed or there was a problem with its management, then bodily difference came to the fore: a private trouble always threatens to become very public. This is problematic because the body out of control has become a key stigmatising image of diseased and sick bodies (Crawford, 1994). Further, some degree of control

in the use and presentation of the body is necessary in order ‘to be acknowledged as a competent social performer’ (Kelly & Field, 1996:246). This is because bodies convey meaning ‘designed to constrain and organise expectations about behaviour’ (Gagnon & Simon quoted in Kelly & Field, 1996:246). There appears to be something of a circular argument here: to be competent is to have body control because lack of control is read as meaning socially incompetent. Hence the question as to why lack of control is interpreted as meaning lack of social incompetence goes unasked.

Moreover, Kelly & Field appear to treat body control as an all or nothing quality, failing to consider whether the consequences of lacking control differ according to the type or degree of bodily control at issue. Further, they do not explore whether bodily behaviour and actions which are *interpreted* by others as lack of control, is *actually* a lack of control. For example, someone with impaired hand movement who spills part of a drink may be observed by others to lack bodily control and to be child like. However, for the disabled person picking up the mug up may have taken extreme effort to restrain unwanted movement and so view any spilt liquid as ‘collateral damage’. Nonetheless, there may be embarrassment all round. So here the link between body control and social competence is about judgements made on the basis of surface appearance of the body and the outcome of body management rather than management itself. In all this, the impairment work, in this instance restraining unwanted movement, goes unnoticed. Similarly, this whole episode may have been avoided if environmental circumstances had been different: for example if a straw had been available or tables been a different height. Thus appearances of some types of bodily control are socially contingent.

A more sophisticated argument about body control and social competence is found in the work of Hughes & Paterson (1999). One of these authors, who has a speech impairment, analyses an incident in which he opened the door to a delivery person who asked ‘Oh, is your Mum not in?’, assuming that he was not a responsible adult. This assumption was based on surface appearances, on ‘aesthetic “evidence” as if (somehow) appearance is an omnipotent guide to competence’ (606/7). Interpreting this from a carnal sociological approach, the authors argue that the

*'social competence of people with impairments is masked, not because of their carnal performance, but because the conventions and norms of "competence" are devoid of "their" carnal information' (607).*

This shifts the analytic focus from appearances of bodily control – ‘carnal performance’ - to the embedded norms of intersubjectivity which are based upon the intricacies of non-disabled bodily function and performances. This shift raises two questions. First, what explanation can be given for those who ignore these norms, who don't view the impaired performance as problematic, and therefore relate to disabled person as competent? The second question which follows from this is how can carnal norms be changed to include the bodily realities of people with impairments and the degree to which carnal norms can accommodate the potentially infinite number of bodily realities and performances. Such change would mean it was no longer necessary for disabled people to adjust to society in order to be assimilated into society on the terms of non-disabled people. In the mean time, disabled people have to do the work necessary to handling encounters in which one party makes false assumptions about, and therefore excludes, the other.

However, the potential of Hughes & Paterson's work to liberate disable people notwithstanding, there is a question here as to whether some experiences of lack of bodily control are inherently or always distressing. In one survey Albrecht & Devlieger (1999) found that the ability to (re)establish control over mind and body correlated with good quality of life. The 43% of respondents who reported a poor or fair quality of life felt that they had lost control of their body, social life and environment. Type or effects of impairment seemed to be the pertinent explanatory issue as it was those who were in pain, continually fatigued or had communication impairments that reported a poor quality of life. Interestingly, one of the common features of these impairment effects was that they made social contact difficult, albeit for different reasons.

### ***Resisting the Work of Impairment***

One final point I want to flag up in this section is that none of the studies (including that of Tighe) consider whether some disabled people fail, refuse or resist doing body work, and if so, what forms this may take. In many ways, the disability movement's

long-standing and on going campaign for independent living can be construed as resistance. This is clear from the definition of independent living as

*'being able to live in the way you choose...having choices about who helps you and the ways they help...it is not necessarily about doing things for yourself'*  
(National Centre for Independent Living, quoted in Hasler, 2006:228)

Here then independence is re-interpreted as choice rather than doing and doing alone. It recognises that disability work can be complex and arduous. Therefore in order to have greater time and energy for social participation it is more conducive to quality of life to have assistance with the doing of disability work. Better an extra hour down the pub than the same time spent taking off one's socks. Campaigning for independent living is a form of resistance that occurs collectively and individually. Collectively, current campaigning is focused upon securing legislation guaranteeing a right to independent living. Locally, resistance takes place as people negotiate care assessments, rehabilitation programmes and so on. This involves challenging health and social care professionals' ethos and practice which is geared to maximising a disabled person's function with the least assistance possible. To do this risks the professional judgement of 'failing to adjust to his or her condition' (Hasler, 2006:43).

## **Conclusion**

In this chapter I have explored two lines of argument. The first of these is that the significance of the onset of impairment, including chronic illness, can be interpreted as a negative disruption to biography, positively as an opportunity for self development – or, presumably, both. To what extent can these different interpretations be accounted for by the perspectives in which they are grounded? In the chronic illness literature, which interprets impairment negatively, the body features as little more than something which, when disrupted by illness, also disrupts a way of life. Moreover, this disruptive body, as little of it as there is, appears to be derived uncritically from biomedicine and therefore conceptualises illness and impairment as an abnormality of the body (see chapter three). Yet little indication is given of how people *actually* experience the body, beyond the fact that it is objectified by the person with chronic illness, in an effort to ensure that it does not

overwhelm the self (Bury, 1992). An interesting line of future inquiry here could be how the relationship between the embodied self and the experience of the body as a source of pain or discomfort mediates the process of biographical disruption.

In contrast to the chronic illness literature, that derived from the personal experience of illness seeks to understand impairment in the context of health, is informed by the embodied self or the experience of the body. Consequently, it suggests that there is a reflexive process of contemplation of the bodily experience of impairment, the outcome of which can be a positive perspective on life. The irony here then is while the body in a given context may be the source of impairment or chronic illness, it is by appreciating the phenomenological, embodied experience of impairment, including the spectrum of feelings and emotions, that an optimistic outlook on life with impairment can be achieved. If this argument is valid then it can add to those who argue for the inclusion of the body and embodiment in the Disability Studies' cannon. It may also be used to ally the fears of those, such as Morris, who fear talking about impairment play in to the hands of those who seek to denigrate or doubt the quality of life of disabled people.

A final point to make here is that the contrast between these two literatures highlights that the evaluation of bodily experience is extremely diverse and unstable. While the concepts of health, illness, chronic illness and impairment refer to differing swathes of bodily experience, the relationship between these swathes, and that between each concept and a bodily state, are highly unstable. This gives scope for disrupting taken-for-granted meanings of these concepts in order to challenge the values imputed to them. Lindsey's health within illness concept is an example of this. This is also a way of challenging medical interpretations of the impaired body. These interpretations are explored in the next chapter.

The second line of argument developed in this chapter is that the consequence of living with an impaired body in a disabling world is the necessity to do various forms of work to the body and with the body. As we saw, for Tighe, this work comprised dealing with disabling barriers as part of everyday life and striving to conform to non-disabled people's standards of health. The burden of this work can in itself

undermine health. Zola (1991) described a form disability work that was quite literally body work: dealing with tiredness and discomfort that emerged from the relationship between his embodiment and social space. Zola chose to hide this work in order to appear 'just like everyone else' (4). With both these examples of disability work, it is not impairment that leads to ill health but dealing with disabling barriers that does. Here then the concept of disability work opens up for theoretical exploration the space between the experience of impaired embodiment and its fleshy encounters with disabling barriers. Such an exploration will be undertaken in chapters six and seven. A further advantage of highlighting disability works is that it problematises the normative underpinning on adapting to chronic illness, which places the onus for adapting without taking into account the social constraints which make adaptation necessary.

## CHAPTER 3

### Biomedicine and its Interpretations of the Impaired Body

#### *Introduction*

This chapter is about biomedicine and the impaired body. It will look at how bodies are interpreted in medical contexts and the implications of these interpretations have for the regulation of the impaired body, both within the medical arena and beyond. One difficulty which needs to be noted straight away is the use of the term “impaired body”. As a category, it seems to have little currency outside Disability Studies and certainly not within biomedicine. Similarly, it is not clear whether individuals use it as a way of referring to their own bodies. Yet despite these limitations it feels vital to use it here as a way of anchoring disabled people’s experience and understanding of their bodies outside the biomedical arena. This is particularly the case in this chapter because its premise is that biomedicine’s interpretations of what can be called the impaired body are predominant but have been increasingly challenged. As Cunningham Burley & Backett-Milburn (1998) point out, we have no ‘innocent’ knowledge of bodies, rather we ‘are always “reading” our bodies through lenses of various interpretive schemes’ (142). In a sense then, in this chapter I am not looking at biomedicine’s interpretations from an ‘innocent’ or neutral position. Rather the category ‘impaired body’ is enabling me to root my analysis in the social model notwithstanding its limitations.

Having clarified this, the chapter will now discuss the principal ways in which biomedicine has interpreted impaired bodies, interpretations which have emerged through medical knowledge and practice. These interpretations will be considered under the following headings:

- Impaired body as abnormal
- Impaired body as in need of fixing
- Impaired body as symbolic failure
- Impaired body as indicator of poor quality of life



Mindful of the fact that medical knowledge is a mode of discourse (Bury, 1986), taken together these interpretations have formed a narrative of the impaired body as abnormal and subject to continuous medical oversight. However, it would be misleading to consider these interpretations as all-embracing, static or unified. As we shall see, developments in medical knowledge and technology result in new forms of perception and discourse. Moreover, these interpretations have been challenged by the social model of disability and by disabled people who become knowledgeable about their own conditions (Jessop, 1996) and develop 'sophisticated' relationships with healthcare professionals (Watson, 2003). So the questions that need to be explored here include the following: to what extent do biomedical interpretations of the impaired body influence disabled people's embodiment and self worth? How have these interpretations emerged? What control do they exert over disabled people individually and collectively?

The structure of this chapter is as follows. It will begin with a brief overview of biomedicine and sociological criticism of it, particularly that criticism which highlights the disembodied nature of biomedicine. The second part of the chapter will explore the interpretations of impairment embedded within biomedicine and which are inexorably related to its normative and normalising tendencies. In the final section of this chapter, I will consider the implications of biomedicine's interpretations of impairment on disabled people's sense of their bodies.

### ***Overview of Biomedicine***

Biomedicine is the model of medicine which describes the key characteristics of the medical knowledge and practice which operates in the Western world. Like most models, the biomedical one is an oversimplification of that which it seeks to explain. It is a 'heuristic device' that provides 'a way of thinking about the truth' rather than the truth itself which may or may not exist' (Scully, 2002:51/2). As such it has been thoroughly critiqued by Medical Sociologists. They have highlighted the ways in which medical practice deviated from the biomedical model (Williams, 2003), challenged the taken-for-grantedness of medical knowledge (Bury, 1986) and, through the work of Foucault and those inspired by him, examined the close 'relationship between...medical discourse and the exercise of power' (Turner,

1995:10) enacted through the body. What I want to do now is outline the main characteristics of biomedicine and discuss the criticisms made of it.

Biomedicine is based upon 'the principle of rationalism' (Barker, 1998:1072) and more particularly, on knowledge derived through the use of scientific principles and methods (Lupton, 2006). This has provided biomedicine with a veneer of legitimacy and neutrality and has bestowed upon doctors a cultural authority. Indeed, GP Dr. Tudor Hart (1988) has argued that the scientific roots of medicine are sometimes exaggerated in order to enhance doctors' professional standing. From this perspective, the body became an object, and illness understood less through the subjective embodied experiences of the individual and more through the medical gaze of the doctor. Thus the 'disease had become more important than the person who harboured it' (Doyal, quoted in Lupton, 2006:91).

Recently this epistemological privileging of medical knowledge has been challenged (Prior, 2003). Current health policy encourages 'patient involvement and partnership in matters of care and treatment' (43). Lay people have become more sceptical about the efficacy and accuracy of medical knowledge (Williams & Calan, 1996) and are now more likely to question doctors' 'motives and judgements' (Cassell, 2004:16). However, as Prior (2003) argues, lay people and doctors have *different* forms of knowledge and expertise and therefore the expertise of one can rarely be substituted for that of the other. Medical knowledge then is still authoritative, albeit that best practice now recommends that it should be tempered with respect and understanding for the patient's view.

These challenges to the privileging of medical knowledge have also been reflected in more theoretical work, particularly those who write from the 'umbrella' of social constructionism (Shilling, 2003). From this perspective, medical knowledge is 'constructed and contingent' and its scientific and objective basis 'held to be myths which serve to disguise the actual struggles and consequences that surround the production of legitimate knowledge' (J. Watson, 2000:20). Thus medical knowledge is problematised and enquiry focuses upon revealing the 'conditions of possibility',

the preconditions and social forces from which medical knowledge emerges (Bury, 1986:145/6).

Another feature of biomedicine is that it is rooted in the doctrine of specific aetiology (Williams, 2003). This doctrine regards all diseases as biological abnormalities (Armstrong, 1994) which have a specific cause that can be identified and successfully treated through medical interventions (Turner, 2000). The degree to which current medical practice conforms to the doctrine of specific aetiology has been challenged (see, for example, Cassell, 2004, Engel, 1977, Turner, 1995). For example, Armstrong (1994) reported a study of people diagnosed with appendicitis who had an appendectomy. Subsequent laboratory tests found that only in 50% of cases did the removed appendix show signs of disease. This indicates that symptoms do not always correlate with underlying pathology and symptoms may be explained by a combination of factors including the social, psychological or biographical. Thus doctors do not act upon the basis of biological information alone.

However, there is a paradox here. On the one hand, biomedicine in general and the doctrine of specific aetiology in particular is predicated upon the Cartesian mind/body split (Lupton, 2006) and the metaphor of the machine is used to describe and understand the body (Synott, 1993). Hence within biomedicine the body is 'radically materialist' and the 'mindful' causation of somatic states is largely ignored (Scheper-Hughes & Lock, 1987:8). Indeed we lack the vocabulary to even talk about the mind-body relationship. On the other hand, medical knowledge does not have direct access to the biological fact. Rather its understanding of the biological is always mediated through the social and cultural. More explicitly, in the post second world war era, there has been a shift from seeing the body as a machine towards an ecological approach to the body, whereby the sick man is seen as an energy system 'in which the balance of forces have been disturbed' (Walker, quoted in Arney & Bergen, 1983:12). In another development, Engel (1977) advanced a biopsychosocial model which would take into account psychological and social factors. However, as Armstrong argued (1987), this model assumed that sociological and psychological disciplines would remain separate disciplines rather than being integrated into biomedicine. It was also assumed that these disciplines

would be subservient to the needs of biomedicine. What this paradox highlights is that biomedicine is not monolithic, and that medical practice is underpinned by a knot of social, biological and cultural factors although it may not always serve the medical profession to acknowledge this.

This cursory overview of biomedicine suggests that it privileges the mind over the body, the objective over the subjective, the biological over the social. This has come to be regarded as the taken-for-granted, naturalistic understanding of the body, one rooted in science and abstracted from individuals' everyday lived body (Toombs, 1992). Bolstered by medical knowledge, it is from these interpretations of the body that impairment has come to be understood in particular ways. It is this that I will now explore.

### ***Impaired Body as Abnormal***

The antecedents of impairment usually begin with the individual sensing that 'there is something wrong' with the body. In keeping with biomedicine's doctrine of specific aetiology, the aim of the diagnosis process is to establish an underlying cause, an abnormality, to explain what's wrong. There is an interesting question about the boundaries between impaired and non-impaired bodies. Does the impaired body emerge from the subjective sense that 'something is wrong with the body', from the biomedical process of objectifying the body to the point where a diagnostic label is attached to it, or from a mixture of the two? There is also a question here about the role and significance of biomedicine in establishing these boundaries. Is it the case, as Thomson (1997) argues, that 'the concept of disability unites a highly marked, heterogeneous collection of embodiments whose only commonality is being considered abnormal' (283)? Given that it is, as we shall see, through biomedical knowledge that bodies are 'considered abnormal' the question becomes to what extent is it possible to interpret the impaired body outwith biomedicine? What are the implications of this?

These are questions which need to be borne in mind here as we move on to consider how abnormality is understood in a medical context and what its relationship is with impairment. Normal, abnormal and pathological can all be regarded as foundational

concepts of biomedicine (Trnka, 2003) and medical practice is concerned with diagnosing disease by assessing how a particular individual compares with a given norm. There are, however, many different meanings of these concepts in biomedicine and they are applied in different ways to different disease processes.

In the context of impairment, Scully (2002) argues that ‘in medical practice, the problematic of “normality” has been reduced to agreeing on the magnitude of deviation from certain numerical “normal” ranges outside of which a person should be considered ill or disabled’. Thus ‘abnormality is *defined* in terms of deviation from the normal state (italics in the original, 49). Here Scully is referring to normal in its statistical sense of a description of the distribution of a particular trait in a specified population. The abnormal can only exist in opposition to the normal (Hughes, 2000).

Scully goes on to make clear that the concepts of normality and abnormality used here ‘are not delivered in an unmediated form from biology’. Rather, they are ‘interpreted through existing understandings of the body in accordance with cultural standards’ (48). In part, these understandings are always contingent upon the current state of biomedical knowledge and technology. What is normal (and thus abnormal), Scully argues, reflects the availability of diagnostic tools to reveal bodily physiological and biochemical attributes and processes, together with the technical ability ‘to quantify’ them (49). So what constitutes a biological abnormality, and hence a disease or impairment, is not somehow natural or given – although it may be experienced as such – but shifts over time. The possible ways of interpreting bodily happenings changes and expands as medicine develops. Scully illustrates this by highlighting the fact that hip fractures and spinal deformities, which used to be considered a normal part of the ageing process, are now classified as the disease osteoporosis (49). So as medicine expands its jurisdiction to include more and more parts of the life course – birth, pregnancy, ageing – what was once considered normal is no longer so.

There is a further sense in which concepts of biological norms are interpreted through culture. Scully hints at it when, in the passage quoted above, she refers to

normality being ‘reduced to agreeing on the magnitude of deviation... outside of which a person should be considered ill or disabled’. Having obtained a statistical norm for a particular human trait or function, a judgement has to be made concerning the degree of deviation from the norm which marks the dividing line between the normal and abnormal. Such judgements, Armstrong (1987) argues, are made on the basis of whether an abnormality interferes with ‘proper functioning’. In other words, impairment is not coterminous with abnormality; there are many abnormalities that do not result in impairment. Nor is impairment wholly biological because what constitutes ‘proper functioning’ is determined socially in terms of what is expected of individuals in a particular society at a particular moment in time. Therefore, ‘the notion of abnormality embedded in disease is not the statistical but the social or ideal’ (1215). To illustrate this with an example relevant to impairment, an abnormality which interferes with the ability to read will only be seen as such in societies that place a high value on literacy.

It is here then that we begin to see that biomedicine is normative: inherent in its foundational concepts of normal and abnormal are ideas about how bodies *should* be and the values attributed to those which are Other. This point can be demonstrated by drawing upon Canguilhem’s (1989) historical study of the relationship between the normal and pathological within biomedicine. His main thesis was that there is no objective, scientific way of determining ‘the normal’, so a ‘biological science of the normal’ is not possible. Rather, Canguilhem sought to show ‘that the pathological state is not a simple, quantitatively varied extension to the physiological state, but something else entirely’ (89). In other words, there is no simple relationship between changes in the physiological or biochemical processes of the human body and the presence of disease.

Tiles (1993), following Canguilhem, argues that values are inherent within medical knowledge itself. This is so because such knowledge contains an assumption that physical health can be defined ‘in purely physicalist, physiological terms via the distinction between the normal and the pathology (normal is healthy) without a whiff of teleology,’ (731). In other words, health has been equated with normal functioning of the physiological body, without mention that normality and/or health

are *aspirations* about what is good for human kind. Ultimately, Tiles argues, perceiving health in terms of normality collapses the two concepts of the normal found in modern medicine: that is the average or statistical norm of physiological function and the normative activity of therapeutics which seeks to restore the statistical norm. The statistical norm which describes what is, becomes the aim of therapeutic medicine via the normative which indicates what should be. Crawford (1994) makes a very similar argument to Tiles and it is perhaps worth quoting here for the purpose of clarification:

*'When the body became an abstracted entity, identical to all other bodies, detached from living situations, health became a concept for describing its normal state. The description became the goal: the restoration or maintaining of normal functioning' (1350).*

Thus impairment is not only a statistical abnormality but also a pathological phenomenon which needs to be normalised via therapeutic medicine – see below. Thus 'through diagnosis, it is possible to determine how deviant one's body is from the norm, and the degree of good and bad health can then be decided from this assessment' (Mercer, cited in Tighe, 2001:512).

One point which emerges from the above analysis is the complexity which surrounds the use of the terms norm, normal and abnormal in biomedicine. Yet this complexity is not usually conveyed in medical discourse, still less in medical encounters. Of course, this may be done from the best of motives: providing information in accessible form. However, it can also be reductive, which is another characteristic of biomedicine which often has negative implications for the understanding of impairment.

This can be illustrated by examples drawn from debates about prenatal diagnosis. In Shakespeare's (1999) review of medical journals and textbooks, the language used to describe an unborn child at risk of genetic disease was negative and value laden. For example, reference was made to 'the burden of an affected child', and that the discovery that a foetus has an abnormality is 'always devastating for parents' (673). What is particularly noteworthy about the last example is the very idea of the child having an abnormality is portrayed as devastating, *regardless of what the*

*abnormality was and its possible implications for daily life.* Abnormality becomes a value judgement, inextricably linked to all that is negative and tragic – and totally disembodied. Impairment is eclipsed by abnormality and abnormality itself becomes ‘devastating’. Yet ultimately, at a biological level, it is nonsensical to think that there can be a foetus *without* an abnormality. Every human body is unique and, as we saw above, each contains many different processes and features which maybe abnormal at any given moment. This diversity is an evolutionary necessity.

Here then we see another instance of biology being mediated by the social, as we saw Scully argue above. In the process, the medical profession constructs a ‘story’ about impairment and abnormality. The notion of a story here comes from Lippman’s (1992) paper on ‘geneticization’, which is also concerned with the effects of biomedicine’s reductionism. She argues that advocates of the project to map the human genome tell stories. The main theme of these stories is that the project ‘will relieve human suffering and improve human reproduction by greatly increasing physicians’ ability to diagnose, treat and predict disease’ (1469). They are told as if they represent objective reality. However, like all stories, they are but one of many different ways of interpreting reality. Lippman goes on to argue that in these stories, where genetics is used to predict a susceptibility to a condition, emphasis is placed on preventing the condition occurring through individual behaviour change, rather than by dealing with the environmental or social factors which may trigger it.

Following Lippman, it can be argued that in the context of prenatal diagnosis a story is woven about the seemingly inevitability of the tragedy surrounding disability and impairment. What gets omitted is any sense of the future personhood of the foetus and that social and economic factors will influence its quality of life as much as its biological make-up. Further, prenatal testing and selective termination may be offered on the basis of a woman’s right to choose, abstracted from the social and economic factors which constrain that choice (Bailey, 1996).

So far, I have sought to establish that the terms normal and abnormal are foundational concepts of biomedicine. However, their meaning silently shifts from the statistical to the normative, from describing what *is* to prescribing what *should*



be. Further, in the medical context, the concept of abnormality often replaces impairment and is negative and value laden. Although medical knowledge is grounded in biology, it is mediated through the social and cultural. Thus it leads to stories or discourses surrounding impairment – amongst other things – that are partial but authoritative and influential as a result of their scientific veneer.

### ***Impaired Body in Need of Fixing***

Having perceived the impaired body as abnormal, it then becomes an object to be fixed, controlled or normalised. Once a diagnosis is made the hope by all concerned is that treatment and recovery will follow. Impairment, however, fractures this hope: by definition it *cannot* be fixed. Instead the impaired body becomes ‘the object of medical supervision’ (De Swaan, 1990:65) to be controlled, managed, researched, normalised and regulated. There is, it seems, a diverse range of social and political forces which exert pressure to change the impaired body, to make it something other than it is. These forces operate and are expressed through and within biomedicine and outwith it, as I will now explore. However, for the sake of convenience, the debate about normalising treatment will be discussed in the next chapter as an example of medicalisation.

While medical knowledge may be based on scientific principles, medical practice is essentially pragmatic: an art conducted in the clinical arena which involves the doctor’s use of skills and techniques to restore the norm in the patient in front of him (Canguilhem, 1989, Cassell, 2004). It is through the ministrations of the doctor that the bodies of patients are judged against the generalities and norms of medical knowledge and its strictures are then imposed upon the body. This desire to fix and normalise both reinforces and is reinforced by the ‘modernist faith in the ability of reason and rationality to drive continued technological and social advancement’ (Scully, 2002:51, see also Thomas, 2007). As this advancement continues, the ‘possibility of fixing renders inescapable the question of whether or not to fix’ (Frank, 2006:68). This question of whether to fix is also mirrored and reinforced by broader social forces which incline people to seek medical fixing. These include the body being viewed as a project (Shilling, 2003), something which is no longer ‘God given’ but which is malleable and can be shaped (Frank, 2006). .

A more specific study of the medical power to control and normalise the impaired body is provided by Disability Studies scholars Sullivan (2005) and Reeve (2002) who draw upon Foucault. Foucault's work is particularly apposite in understanding control of the body because one of his main concerns is the body and the institutions – of which medicine is a significant one - that shape it (Shilling, 2003). This shaping occurs through the exercise of biopower, a subtle mechanism to make a 'docile body that may be subjected, used, transformed and improved' (Foucault, quoted in, Rabinow, 1984:17, Gastaldo, 1997). Of particular interest here is the concept of normalising technology, an aspect of biopower, which classifies and 'controls the "anomalies" of the social body' (Tremain, 2002:37) through 'the power to qualify, measure, appraise, and hierarchize... it effects distribution around the norm' (Foucault quoted in Tremain, 2002:36).

An example of a normalising technology relevant to disability is rehabilitation. This involves first the identification of an anomaly, an impaired body adjudged by the medical or related profession to be in need of rehabilitation, second the spatial placing of the anomaly, that is arranging for the disabled person to be placed in a rehabilitation facility, and thirdly, the anomaly undergoing 'therapeutic or corrective' (Tremain, 2002:37) treatment such as physiotherapy or occupational therapy. Particularly when broken down into these three components, it becomes clear that many of the processes that disabled people have to go through in everyday life to get the support they need, from completing a welfare benefit form to getting a piece of disability related support or equipment, are forms of normalising technology. This technology is a form of bureaucratic, constraining – Foucault calls it disciplinary – power underpinned by medical interpretations of the impaired body. The operation and effect of this power, which is enacted rather than possessed (Mills, 2006), is often obscured because it operates through self surveillance. This means that the outcome of disciplinary power 'seems for all intents and purposes to be expressive of a subject's personal desires and individuality' (Tremain, 2002:37). The final point here is that normalising technology doesn't make the anomaly normal but makes the individual able to live within 'the band that binds the [statistical] normal centre with the boundary zones that must not break' (Waldschmidt, 2005:196). In other words, the abnormal, disabled people may be geographically placed within society but their

presence is rendered invisible or 'effaced' (Stiker, 1999:131) because social and environmental structures do not incorporate their needs.

Having considered Foucauldian conceptual tools, I will now look at how they have been used to analyse the role of biomedicine in controlling the impaired body. The first example I will look at is Sullivan's (2005) empirical study of rehabilitation of people with spinal injuries in New Zealand. This manages to capture the ambivalence of the rehabilitation process: it entails medical control of the impaired body but without this control disabled people's quality of life is likely to be significantly compromised. This ambivalence towards medical intervention designed to optimise function was seldom acknowledged within the early days of Disability Studies (see, for example, Finkelstein, 1980, Oliver, 1990a but see also chapter four).

Sullivan goes on to argue that, when paralysed, the body becomes an object of medical power which is 'subjected to intense diagnosis, classification, monitoring, and discipline in order to render [it] knowable and productive' (30). In effect, individuals lose possession of their body 'in terms of knowledge and control' (31). For example, when repositioned on the bed, one research participant reported querying whether she was in the correct position because it was causing pain. In response the nurse said 'how would you know? You've just arrived here' (32). In other words, the participant's experiential knowledge was totally dismissed and her pain ignored. Alas controlling doesn't necessarily mean caring. When it came to setting the goals of their rehabilitation, participants felt they were just slotted in to a pre-existing programme based upon textbook explanations of what an idealized person with a certain type and level of injury should be able to achieve. Thus one participant commented 'It's like they are trying to turn you into a cripple' (35).

Hence Sullivan argues that disciplinary power not only controls the body but also influences subjectivity. The body and what is done to it shapes identity although not in a deterministic way because the self is 'fragmented into antagonistic sites of power' (Haber, quoted in Sullivan, 2005:31). These different sites make different subject positions possible, that is they allow for the subject to have a number of

identities. This in turn enables individuals to resist normalisation by moving between different identities.

One final point Sullivan makes is that the healthcare professionals prescribed and taught the techniques participants were to use to manage their own bodies for the rest of their lives. In doing so, on the one hand healthcare professionals retained control over participants' bodies outwith hospital, while on the other making participants responsible and accountable for their well-being notwithstanding the medical complications of living through a spinally injured body. Reeve (2002) takes up this point by exploring the psycho-emotional effects of self surveillance or what Foucault (1988), in his later work, called technologies of self. Such surveillance occurs where 'people develop an awareness of how they are seen through the gaze of another and then modify their behaviour via self surveillance to attempt to make themselves acceptable' (500). Reeve recognises that self surveillance can facilitate personal autonomy yet also highlights its emotional cost by drawing upon her experience:

*'non-disabled people who criticise my failure to adhere to apparently simple self surveillance tasks fail to appreciate the emotional costs of having to carry out tasks they do not have to do themselves. These tasks are yet another reminder of my 'abnormality', and I am held responsible for failing to contain and render invisible that difference from the norm' (500).*

There are several points that can be drawn from this. First it is notable how doctors transfer the responsibility for routine management of the impaired body to the individual at the same time as remaining in control over this body. Control is maintained both through teaching self care techniques sanctioned by medicine and making the individual accountable to healthcare professionals to ensure the 'correct' techniques are followed. Through these processes judgements are made about her moral worth. Second, in part self surveillance has to be done to protect the sensibilities of others so that the demands and particularities of the impaired body are 'rendered invisible'. At the same time, Reeve is forced to become aware of her abnormality, to adopt a biomedical interpretation of her body so as to normalise herself to others. Third, from Reeve's emphasis it is clearly significant that it is non-disabled others who impose upon her the necessity for self surveillance. This imposition occurs with little empathy for the embodied experience of impairment

including that of having one's routine body tasks subject to professional instruction and scrutiny.

Shildrick & Price (1998) link biomedicine's attempts to control and regulate the impaired body to political and social purposes. They suggest that in modernity, the body 'must appear invulnerable, predictable and consistent in form and function' because peculiarity threatens paradigms of sameness and difference on 'which western epistemology, ontology and ethics are founded'. The impaired body is one such peculiarity. Hence they argue that treatment decisions 'are all acts or omissions serving to continually reinforce and re-create medical notions of disabled and [sic] able-bodied' (227). In doing so, predictable, uniform bodies are positively valued.

One of the implications of Shildrick and Price's argument here is that the categories disabled / non disabled are not fixed but fluid. Hence it is always difficult to pin down the nature of disability.

What is not clear here is the extent to which this reinforcement of the disabled/non-disabled binary is intentional on the part of the medical profession or individual healthcare professionals. There also appears to be an assumption here that medical practice divides people into the binary categories of disabled/non-disabled. But it is not clear that this is the case within the clinical arena. Medical practice identifies abnormalities and then classifies those into disease categories which are not readily divisible into the disabled/non-disabled dichotomy. This is because such categories do not indicate the severity of the disease or whether it signifies impairment or disability. Arguably it is through doctors' roles as gatekeepers to welfare services that they are required to pronounce someone as disabled or not (see chapter four).

### ***Impaired Body as Symbolic Failure***

Disabled feminist Wendell (2003) argues that if the *raison d'être* of biomedicine is to fix broken bodies, disabled people become its symbolic failure. Ultimately, the desire to fix gives rise to a cultural myth that the body can be controlled. This is reinforced by 'a strong tendency in scientific medicine to pretend that the myth of control is the truth' (94). Disabled people shatter this myth because, as Wendell

points out, those with chronic illness or impairments that cannot be cured come to 'symbolize the failure of medicine...to control nature'<sup>3</sup>(Wendell, 2003:96). This symbolism seems to operate in a number of contexts. One of these contexts is the organisation and funding priorities of the health service. Acute care is usually better resourced than care of those with long term chronic illnesses or impairments. Further, the former is usually held in a high esteem because it involves 'cutting edge' medicine and the necessary heroics of life saving. By contrast the latter are regarded as 'low-prestige care' and are often referred – or 'dumped' as Illich (1990:123) puts it - to health care professionals lower down the medical hierarchy. Further services specifically targeted at disabled people, such as the wheelchair service or rehabilitation wards may be under funded and geographically marginalised within hospital or community premises.

Disabled people may also be a symbol of the failure of healthcare professionals, particularly where they are unable to alleviate bodily suffering (Frank, 2002). In this context, biomedicine's perception of impairment or incurable illness is that presents something of an embarrassment, appearing to be in need of medical attention and yet professionals have little to offer by way of treatment. Disabled people may experience this in terms of the medical profession being 'disinterested, and are disappointed if it [i.e. the medical profession] does not provide advice and support' (Harrison, 1993:212). For some disabled people, this results in feelings of isolation, of being abandoned to manage their impairment alone.

### ***Impaired Body as Indicator of Quality of Life***

A further way that the impaired body has been interpreted by biomedicine is as having less value than the non impaired body. This interpretation can be linked to

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<sup>3</sup> Wendell's evocation of nature is interesting here. Although probably unintentional, it suggests that the impaired body is somehow against nature, that biomedicine's role is to control and correct nature's 'mistakes'. The implication then is that the impaired body is unnatural as well as abnormal. It seems as wherever the impaired body is, it is rejected.

the normative drive of medicine where upon the abnormal or impaired body becomes devalued and inferior to 'the normal body'. As Canguilhem (1989) put it 'normal is polemical because it devalues what does not fall under its auspices' (239). As I will explore below, one of the ways in which this devaluation manifests itself is through the use of quality of life judgements. Such judgements are made both quantitatively through the use of instruments designed to measure quality of life and qualitatively when healthcare professionals invoke quality of life as a factor to be considered in clinical decision making.

Quality of life debates first surfaced in the 1970s as a basis for rationing access to medical intervention. They were prompted by advances in medical technology which could sustain 'mere biological life' almost indefinitely but such life often did not have capacity for consciousness (Wasserman, Bickenbach & Wachbroit, 2005). Having made 'mere biological life' possible, the medical establishment then began questioning whether such life had sufficient quality to make it worth living. In particular, there have been ethical discussions as to the circumstances in which illness, incapacity or impairment makes quality of life so poor that life saving or life prolonging medical interventions should be withheld or withdrawn in the full knowledge that the outcome will be death.. Similar debates have also taken place about the ethics of prenatal diagnosis, including genetic testing and the use of new reproductive technologies. In the recent past, doctors were 'relatively free' to decide upon and then withhold or withdraw treatment. Now, however, with the 'growing emphasis on the right of patients to play a key role in such decision-making' that freedom has been circumscribed (Riddell, Pearson & Watson, 2000:42).

Quality of life judgements have been problematised within Disability Studies. The key issue has been that non-disabled people, especially doctors, have a tendency to assume impairment necessarily leads to an impoverished quality of life. This tendency has been attributed to a number of factors including: prejudice against disabled people (Campbell, quoted in Disability Rights Commission, 2004, Morris, 1991); fears that disability is a 'fate worse than death' (Shakespeare, 2006:118) and a personal tragedy (Reindal, 2000). Further it has been noted that some health professionals disbelief that disabled people are able to pursue 'life plans they find

satisfying' (Ashe, quoted in Miller, 2006:220). There is, therefore, a huge discrepancy between how disabled people assess their own quality of life and how healthcare professionals assess it. This has been dubbed the 'disability paradox' (Albrecht & Devlieger, 1999).

### *Disability Paradox*

One of the ways in which biomedicine expresses its devaluation of disabled people is through quality of life judgements. This has been implicitly challenged by the disability paradox, whereby disabled people report 'that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence' (Albrecht & Devlieger, 1999:977). As we saw in chapter two, Albrecht & Devlieger accounted for this discrepancy through balance theory 'where the experience of well-being and life satisfaction is contingent on the person's achieving balance between body, mind, and spirit' (978). This suggests that disabled people's quality of life is not determined by either (or both) impairment or disability alone but also by personal resources and general outlook on life. This is something which appears to have been overlooked not just by the medical profession but also by many commentators involved in bioethical debates about beginning/end of life decisions.

This is the case for Brock (2005), who offers an alternative view of the disability paradox when justifying prenatal diagnosis and selective termination. He suggests that while some people do adjust and accommodate disability, this is not the case for others. However this appears to be an assumption as he does not provide any evidence to make this point. This is somewhat surprising given, as we have seen, that it is precisely this assumption that disabled people have highlighted as problematic. Nevertheless Brock goes on to argue that because it can be predicted (before birth) that *some* disabled people will experience a reduced quality of life, policies aimed at preventing disability can be justified on this basis. What this seems to overlook is that prenatal diagnosis cannot usually distinguish between those impaired fetuses which would, if born, have a good quality of life and which would not. Therefore Brock's argument here suggests that an impaired foetus that has the potential to have a good quality of life is 'collateral damage' for those impaired



fetuses that potentially would have a poor quality of life. In part this is so because there appears to have been little attempt to isolate which factors tip the balance between a good or poor quality of life or whether such factors can be identified before birth. Further, for any condition diagnosed before birth, it is rarely possible to predict the severity of the condition and how it would affect any individual.

As an aside here, it is interesting to note that some disability activists, for example Morris (1991), argue that there are some conditions where selective termination is justified, for example, Tay Sachs which reduces life expectancy to 5 years or Lesch-Nyhan which causes a compulsive tendency to bite off one's own fingers. Shakespeare (1998) made a similar argument saying that because different impairments have different effects a nuanced approach was needed which recognised that it was acceptable to test for some impairments and not others. More recently, however, Shakespeare (2006) has said such an approach makes the disability rights argument against prenatal diagnosis inconsistent. While that may be true, it is nonetheless an attempt to engage with the quality of life debate rather than the, perhaps easier to defend, position of being against all forms of prenatal diagnosis. However, more thinking is needed to try and draw out the criteria which make prenatal diagnosis justified for some conditions and not for others.

Brock's second justification of prenatal diagnosis is that the process of adapting to and living with disability is 'burdensome' even if it is ultimately successful. Thus, he goes on, this burden should be avoided where possible. Perhaps this argument is a response to the criticism that quality of life measurements fail to take into account the process of adapting to the onset of impairment (Menzel *et al*, 2002). During the process people may experience grief, loss and the sheer day to day difficulty of impaired embodiment in a disabling society. However, there comes a point, as Albrecht & Devlieger's research indicated (see above), where impairment becomes incorporated within a new outlook on life. While Brock acknowledges the adaptation process, he suggests it should be avoided at all costs. But this seems to ignore the moral distinction between different types of impairment prevention programmes mentioned above, that is, those which prevent an impairment from occurring and those that involve eliminating a potential life *because* it has an

impairment. It makes great sense to prevent impairment occurring in order to avoid the burden of adapting to impairment. However, this becomes less clear cut when prevention is only possible through selective termination. There are many events during life which can be burdensome, for example, child bearing or the death of a loved one. Yet saying that a life event is burdensome is not the same thing as saying that one does not want to live *because* of that burden (Silvers, 2005).

A third reason Brock gives for discounting disabled people's own assessment of their quality of life is that he argues quality of life isn't entirely a subjective matter. Amundson (2005) questions this by asking what ignorance burdens disabled people to such an extent that their assessment of quality of life is flawed. By the same token, what enables the 'non-disabled majority' to avoid this ignorance and make accurate quality of life judgements (112). In other words, why is a non-disabled person's judgement of a disabled person's quality of life more reliable than that of a disabled person? Brock would probably answer that the non-disabled person's judgement is objective. Any objective judgement would, Brock suggests, need to recognise that 'there are activities, and accomplishments and personal relations that actually make up what could be called the objective content of [the] life' (69). The implication here is as if disabled people have a sort of 'false consciousness', which means they do not realise that their quality of life is poor. If, for the sake of argument, this is accepted, where quality of life judgements are used to assess the value of a medical intervention for a disabled person, surely this false consciousness doesn't matter because the disabled person is satisfied with the quality of life achieved.

However, the work of Menzel *et al* (2002) highlights a further complexity here. They explore the implications the process of adjusting to disability has on quality of life judgements. This process contributes to understanding the disability paradox, the discrepancy between non-disabled and disabled people's assessment of a disabled person's quality of life. When a non-disabled person makes a judgement about a disabled person's quality of life she has no way of taking into account that her own attitude towards having an impairment may change if they *actually* had an impairment. In other words, the non-disabled person's judgement includes fears

about having an impairment rather than – or in addition to – the reality of living with an impairment. Thus ‘the adapted patient is in a privileged position “in regard to facts about the experience of having her disability”’ (Menzel *et al*, 2002:2153).

But ultimately Menzel *et al* reject using this privileged position to inform quality of life measures. This may feel counter intuitive. Yet to do so would result in discrimination against disabled people. This is the case because an ‘adjusted’ disabled person may make fewer gains from health services than an ‘unadjusted’ disabled person. As the allocation of health resources using quality of life judgements are based upon maximising health gain, an ‘adjusted’ person would have a low health gain and thus would be allocated fewer health resources. This would penalise all those who made a ‘laudable effort’ to adjust. This, the authors argue, would be unjust and so they conclude that ‘laudable effort plays an important role in creating and sustaining genuine moral doubts about the use of adaptation-shaped values’ (2156) in quality of life measures.

The arguments above highlight the fraught nature of quality of life judgements, something borne out in attempts to formulate policy and practice based on such judgements. A piece of Scottish-based research looked at the policy and use of placing ‘Do Not Attempt Resuscitation’ (DNAR) notices on the medical records of disabled people. The research included analysis of relevant policy documents from Hospital Trusts and Health Boards. While around half of these indicated that quality of life was key to deciding ‘whether CPR should be administered’ there was ‘a lack of clarity as to the areas covered by the term’. This was recognised by the small number of consultants interviewed as part of the research. They also acknowledged that quality of life judgments were highly subjective and ‘open to different interpretation by different doctors’ (Riddell, Pearson & Watson, 2000).

## **Conclusion**

In this chapter I have sought to consider the various ways in which medical knowledge and practice has interpreted impaired bodies. These suggest that the impaired body is wholly negative and a key determinant of a (poor) quality of life. One of the questions this raises is whether these interpretations influence disabled

people's sense of embodiment, a question that I will explore through my data analysis in chapter eight. Similarly, the chapter which follows the present one will look at medicalisation to illustrate the extent to which biomedical understandings of impairment have influenced both the spatial placing of disabled people in the physical and social environment and access to social and economic resources.

Here, however, it is perhaps useful to note that the expanding literature of sociology of the body has begun to explore the relations between embodiment and biomedical knowledge. For example, Shilling (2003) has argued that the 'social meanings which are attached to particular bodily forms and performances tend to become internalised and exert a powerful influence on an individual's sense of self and feelings of inner worth' (73). Given that many of the social meanings attached to the impaired body have biomedical roots, it is tempting to speculate that disabled people's sense of self and embodiment are to some extent shaped both by biomedical discourses or narratives about the impaired body and individual medical encounters.

However, one has to be careful here and allow for the *possibility* that some may resist biomedical interpretations of the impaired body. For example, Williams & Bendelow's (1998) study of people with various types of arthritis explored how impairment influenced feelings about body. One of their findings was that doctors' and patients' had different bodily concerns: the former tended to focus on 'management of bodily manifestations of disease' such as pain whereas the latter were primarily concerned with 'body perception and feelings' (137). Similarly, Cunningham-Burley & Backett-Milburn (1998) point out that knowing about the body 'may not affect how one feels' about it (157).

There are also signs suggesting that disabled people actively resist biomedical interpretations of their bodies both at the level of medical encounters and discourse. For example, the husband of an activist placed a photograph of his wife receiving her doctorate in a prominent position on her hospital bed. This was to remind healthcare professionals that 'she had everything to live for' after a consultant had said '[i]f you go into respiratory failure - and it's looking likely - then I'm sure you won't want to be anywhere near a ventilator' (Campbell, 2004).

At the level of discourse, disabled people both within Disability Studies and beyond have, as was seen above, been sharply critical of doctors' quality of life judgements in the context of beginning/end of life decisions. This has added significance when the reluctance of disabled people to engage with health related issues is recalled (see chapter one). The bioethical sphere seems to be the one exception to this. This could be seen as ironic insofar as it is the one sphere where the number of disabled people having direct personal experience of the procedures involved is likely to be smallest. Yet the point of connection is the experience of invalidation and prejudice.

## CHAPTER 4

### Medicalisation, Disability and Impairment

#### *Introduction*

This chapter is about the medicalisation of disability and impairment. It will consider how biomedicine's interpretations of the impaired body, explored in the last chapter, have permeated social and cultural relationships and shaped social responses to disability. These responses have often been constraining, restricting the social spaces where the impaired body can be, the powers to which it routinely has to submit and how its very fleshiness has been gazed at, touched and surgically shaped. This will be demonstrated by tracing the roots of the process of medicalising disability and exploring the implications of one form of medicalisation - healthcare professionals acting as gate keepers to a range of welfare and social resources on which disabled people have to rely. Finally, debates about what has been dubbed normalising treatment will be considered. To put all this in context, an overview of Medical Sociology's debates about medicalisation will be given.

#### ***Overview of Medicalisation Debate***

The medicalisation thesis emerged in the early 1970s as a sociological critique of the role of biomedicine in capitalist society. One of its core concerns was that 'more and more of everyday life [was] coming under medical dominion, influence and supervision' (Zola, 1983:295). This was regarded as 'a troubling phenomenon' (Zola, 1991) because it expanded the range of bodily states and behaviours defined and diagnosed as illness. Then cultural forces dictated that these illnesses needed to be explained, treated and managed through the application of biomedical knowledge. There can be undoubted benefits to this process, particularly at the level of doctor – patient interaction: for example, more women were able to access pain relief during childbirth as pregnancy became increasingly medicalised (Kohler Riessman, 1993). But it has also meant that common life events such as childbirth, death and disability become seen as a problem needing a technical and often a technological solution. Thus Zola (1991) argues that medicalisation can be dehumanising, that what previously was done to the body by a lay person, is now done by an expert or a

machine. This raises the fear that increasing medicalisation may undermine people's ability to care for themselves and result in life becoming a 'pilgrimage through check-ups and clinics' (Illich, 1990:87).

As biomedicine expands insidiously, its jurisdiction becomes a 'major institution of social control' (Zola, 1972:487). For Zola, this means that medicine becomes 'the repository of truth' (487): as people once turned to religion, they now turn to medicine for moral guidance about what we do with our bodies and this guidance becomes technical and determined in the name of health. A pertinent example of this is how legislators look to the medical profession for guidance when drawing up regulations on the time limits for selective termination following prenatal diagnosis. This guidance often focuses upon technical issues such as the stage in pregnancy when tests can be carried out rather than the morality of the process and its implications (Bailey, 1996).

On a slightly different tack, Conrad & Schneider (1992) argue that medical institutions exercise social control as agents of the state. They have the authority to identify and define 'certain behaviours, persons and things' (8) as problematic and to solve them by medical means. This involves individualising and depoliticising social problems foreclosing the option of solving them through social intervention or political change. Here the purpose of social control is to secure adherence to social norms specifically by using medical means to 'minimize, eliminate or normalise deviant behaviour' (242). This understanding of medicine as social control resonates with one of the key criticisms made of the medicalisation of disability: that it focuses upon individual solutions to disability rather than political ones which require the removal of disabling social barriers (Barnes, 2003).

Recently, one of the main criticisms of the medicalisation thesis is that it has failed to take into account the role of the patient (see, for example, Ballard & Elston, 2005, Broom & Woodward, 1996, Williams & Calan, 1996). Within the early writings on medicalisation, patients tended to be 'portrayed as victims of medicalisation', helpless in the face of ever growing medical power (Broom & Woodward, 1996:360). This view is now regarded as inaccurate. One reason for this is, as

Lupton (1997a) argues, since the 1970s lay people have adopted a more consumerist approach to health care. They have also become more 'sceptical of modern medicine' (Williams & Calan, 1996:1611), more willing to challenge expert opinion and more likely to be active participants in the doctor-patient relationship. This may be especially so for those disabled people who have to make frequent use of the NHS, and who become very skilled and sophisticated in establishing relationships with healthcare professionals (Watson, 2003) (see also chapter eight).

None of this undermines the medicalisation thesis, but it does suggest that the behaviour of patients, the needs they articulate, the types of treatment they request, should be considered as one dynamic of medicalisation. These needs and requests are influenced by the notion that health is a moral pursuit (Crawford, 2006). This is illustrated by recent increases in women's requests for surgical reductions of labia (Liao & Creighton, 2007) and for fertility treatment (Becker, 1992). However, one has to be careful about overstating the power of consumer demand because it is necessarily contingent upon the medical expertise and technology having been developed to deal with the problem in the first place. All this raises two questions. In the early years of the debate, the term medicalisation was pejorative (Lupton, 1997b). Is it still a 'bad thing' or are there some situations where medicalisation is desirable (Broom & Woodward 1996)? The second question is whether this concept of medicalisation is still useful? In this regard, Lupton (1997b) has noted the growth of Foucauldian analysis which, while not framed within medicalisation, analyses similar territory to it, namely the way 'individual lives are profoundly experienced and understood through the discourses and practices of medicine and its allied professions' (94). As we saw with Sullivan's and Reeve's work in the previous chapter, this type of analysis has been applied to aspects of disabled people's healthcare experiences and offers a more finely grained analysis of the way micro power constructs disability in day to day life. In particular, it recognises that the medicalisation of everyday experience, what Foucauldian's would dub medical surveillance, does not only refer to face-to-face medical interactions 'but also to the self-regulation individuals engage in because they internalize medicine's gaze, they incorporate it into their understanding of their embodied selves and the world.' (Lorentzen, 2008:53).



What emerges from this overview is that the phenomenon described as medicalisation is problematic. Medicalisation is “troubling” (Zola, 1991) because it increases medical jurisdiction over more and more areas of social life and operates as a form of social control through the labelling of more and more bodily states as medical problems. This can sometimes have the effect of depoliticising social problems and reinforces the cultural authority of healthcare professionals as experts. Similarly, medicalisation as a conceptual or an analytic tool is problematic. It provides no basis for evaluating whether medicalisation is desirable nor allows consideration of the role played by consumer or patient power in pushing for and/or resisting medicalisation. Perhaps more fundamentally, it is often not clear how medicalisation relates to other social forces. In the early work, the social forces implicated as the cause of medicalisation were the expansionist tendencies of the medical profession. However, this is a view that is no longer sustained (Ballard & Elston, 2005), nor are healthcare professionals necessarily involved in all instances of medicalisation. In short, the concept of medicalisation as both a social process and conceptual tool is somewhat amorphous, having different meanings at different moments of time and for different scholars.

Nonetheless, it is useful to review the Disability Studies’ literature on medicalisation because it is one of the ways in which it has critically engaged with the medical model of disability and its social and political ramifications. In presenting this review I will use Conrad’s (1992) schema. This posits that medicalisation occurs at three different levels of society, the conceptual, the institutional and interactional. This facilitates the analytic differentiation and identification of different instances of medicalisation and the relationships between them.

### ***Medicalisation at the Conceptual Level***

#### ***Medicalisation as Ideological***

Disability Studies’ scholars have used the concept of medicalisation to identify and challenge the deeply entrenched medicalised view of disability which underpins many of the social institutions that structure and regulate disabled people’s lives. This usage emanates from Oliver’s (1990a) heuristic model developed to link the

creation of disability through the capitalist mode of production (see chapter one) with the view that disability is a medical problem and a personal tragedy. Oliver draws upon this model to analyse how the medicalisation of disability operates as an ideology or, in terms of Conrad's schema, operates at the conceptual level.

Oliver's (1990a) model posits that during the early stages of the industrial revolution, disabled people were excluded from the newly industrialised workplace and that this process was managed by the emerging medical profession. This was facilitated by two historical forces from which the ideology of the medicalisation of disability emerged. The first of these was developments in medical knowledge occurring in the second half of the 19<sup>th</sup> Century. In particular, the development of "germ theory" meant that the immediate cause of diseases could be located within the human body. This underpinned the doctrine of specific aetiology and shifted the medical gaze away from the relationship between the patient and the environment, and towards the inner workings of the human body (Armstrong, 1983). This was facilitated by the development of medical technology, such as the stethoscope, which gave doctors privileged access to the body (Oliver, 1990a, Stone, 1984), by-passing the subjective experience of the patient. As we saw in the previous chapter, in this context impairment became interpreted as an abnormality requiring medical intervention and this reinforced impairment as a bodily problem.

The second historical force from which the ideology of medicalisation emerged was what Oliver (1990a) identifies as the core capitalist ideology of individualism. He argues that "the individual" was an ideological construction necessary to legitimise the shift from the family as the unit of production in feudal times to the individual as the unit necessary for industrial production. At the same time

*'the rise of mechanised forms of production introduced productivity standards that assumed a 'normal' (that is to say, usually male and unimpaired) worker's body and disabled all others' (Gleeson, 1999:106).*

So the individual or average worker was constructed as a body which quite literally fitted into the physical and temporal regimes of industry. The category of "a disabled person" was created to account for and control one of the groups whose members who could not bodily conform to the needs of mechanised production.

Hence the impaired body was identified through the needs of capitalism. In making this argument, Oliver also draws upon Foucault's notion that the very idea of madness as an individual pathology was not possible without the notion of "sanity". Thus disability, as with madness, was a 'complex and non-intentional social product' (Hirst & Woolley, 1982 quoted in Oliver, 1990a:46/7) that emerged as a result of capitalism's need to define the individual worker.

Combining these two historical forces, Oliver argues that the medical profession was in a social position which enabled it to legitimise disabled people's exclusion from the workplace. It did so on the basis of 'classifying and interpreting disability in medical terms' (Finkelstein, 1993:4) rather than what would now be described as the inaccessibility of the workplace. This marks the beginning of the medical profession acting as gate keepers - that is being situated in a position of control over disabled people by first interpreting the body as impaired, and then using that interpretation to determine eligibility for welfare resources. Simultaneously the medical profession was charged with distinguishing between "deserving" and "undeserving" poor. This served the purpose of social control by reinforcing work and the exchange of labour for wages as the primary source of income distribution. Thus those considered undeserving by virtue of being capable of work were given no assistance, forcing them back to work or into starvation. The deserving too were socially controlled by being sequestered in particular institutional spaces such as the workhouse or asylums (Borsay, 2005).

Oliver's argument is that the medicalised view of disability became an ideology through the medical practices of gate keeping, and so has a materialist base. It is possible to conjecture that the general population came to accept the official view that disabled people could not work due to their impairment. Using Gramsci's concept of hegemony, Oliver (1990a) argues that this view, this medicalised ideology, became the taken-for-granted way of thinking about disability. It is this that the disability movement has challenged. While the thrust of Oliver's account of medicalisation as ideology is most plausible, it is schematic as he acknowledges. This becomes apparent when looking at more historically grounded, if less all-embracing, accounts of the origin of the medicalisation.

Borsay explores the origins of one instance of medicalisation by analysing the collaborative relationship between local charitable institutions and orthopaedic surgeons in the early years of the 20<sup>th</sup> century. Part of the charity's role was medical surveillance which involved visiting families and referring disabled children to surgeons for treatment. This resulted in 'painful medical intervention in the bid to police any deviation from the physical norm' (2005:53). Moreover, it also meant families were subjected to 'intrusive socio-psychological scrutiny' (53) to secure compliance with medical orders and admonished to aspire to middle class Victorian values of thrift, self help and independence.

This analysis raises a number of useful points. First, Borsay's approach uses Foucault's notion of disciplinary power which is localised and diffuse. Such power operates not through institutions but comprises 'instruments, techniques, procedures, levels of application, targets' (Foucault, 1991 quoted in Borsay, 2002:105). This allows Borsay to look beyond the role of the state and economic interests to highlight the practice of medicalisation. She can then highlight a social control mechanism in the relationship between the families of disabled children and the visiting officers of charitable organisations.

The second point that Borsay's analysis highlights is a form of medicalisation that is proactive, what Foucault terms surveillance. It involved identifying and *seeking out* disabled children, who were assumed to need medical intervention. Moreover, 'the idea that the recipients [who were offered treatment], perceived here in eugenic terms, might resist assistance was alien to most early twentieth-century service providers' (2002:111). The reference to eugenics indicates that the treatment offered was not (just) in the humanitarian interests of the children concerned but in the surgeon's interest, supplying him with patients and charitable funds to cover the costs of treatment. Both of these things were significant at the time because orthopaedic surgeons were the 'poor relation' within medicine and anxious to bolster their reputations (Borsay, 2002:110). Further such treatment was 'legitimated by recourse to economic rationality': by treating disabled children the hope was that they would become economically productive in adulthood (111). Thus such treatment was also in the interests of the state.

From this historical account of the emergence of medicalisation, several features emerge which resonate with the contemporary relationship between medicalisation, medical practices and disabled people. The first of these is the association between eugenics and disabled people's health care with the fear being that this is an association that still continues (see, for example, Priestley, 2002, Rock, 1996). The other feature that has a contemporary resonance is that medicalisation can be proactive and serve interests other than or in addition to the particular patient being treated. An example of this is prenatal testing which 'seeks out' impairment in the fetus and in doing so medicalises both mother and fetus (Bailey, 1996).

There is one further historical account I want to consider and that is Stone's (1986) analysis of doctors' gate keeping role. At the heart of Stone's analysis is what she calls the state's distribution dilemma: that is how to distribute public resources on the basis of need to the deserving poor without undermining the necessity for all those capable of working to sell their labour in exchange for wages. To resolve this dilemma, a validating device was needed to distinguish between the deserving and undeserving poor. This was problematic, Stone argues, because there was no consensus about the type or level of disability that rendered someone incapable of work. Further, disability 'could be feigned' (23), the motivation for which was to have a legitimate reason for not working. Stated this way, the implication is that disability existed prior to attempts to validate it, an implication sustained by Stone's evidence that lay magistrates originally validated which paupers were sick. This was done on the basis of the testimony of acquaintances rather than that of the medical profession. So in this instance gate keeping involved validating the individual's own interpretation of the body. This differs from Oliver's position which posits that a medical interpretation is imposed upon the body thus producing disability.

One of the points that Stone draws from the involvement of magistrates is that the connection between disability and its medical definition is 'an artefact of history' (28). This suggests that the medicalisation of disability is something of an accident of history and not integral to the social and cultural forces of capitalism or modernity as Oliver and Hughes (see below) describe. But this may reflect the limitations of Stone's method, which consists of constructing ideal types, abstractions formed from

an amalgam of historical detail gleaned from a number of countries and moments in time. This means that the historical data presented is ‘selective and ambiguous’ (Gleeson, 1999:64) so we can’t be sure of the particular circumstances in which lay magistrates played this validating role.

### *Medicalisation as a Feature of Modernity*

Complementing Oliver’s notion of medicalisation as ideology, Hughes (2002) argues that there has been a ‘historic partnership between modernity and medicalisation’ to create ‘a hegemonic conception of disability as the outcome of biophysical or mental impairment’ (58). Modernity, Hughes argues, comprises two seemingly opposing tendencies. The first is to obliterate difference and thereby maintain modernity’s ‘overbearing sense of order’ (1999:157). The impaired body seen through biomedicine’s lens is disorderly, ‘faulty’ and so offends this sense of order. It also offends another modernist belief, the ‘triumph of reason’ (Hughes, 2002:58) to solve any problem through the application of rational knowledge. Within this tendency, the impaired body is seen as a corporeal problem that medicine then normalises through, for example, rehabilitation. The aim of such normalisation was to change the individual to fit in to society with minimal disruption to the latter. As Stiker (1999) puts it, everyone can have a ‘place in the group of the able (the normal)’ whatever burden that entails for the individual (135). The aim is to make identical, *without making equal* (150, italics in the original).

The opposing modernist tendency was its ‘constitution of alterity’ (Hughes, 2000:557), its social processes that marginalised and “Othered” those considered a threat to order, including disabled people. Crawford (1994) has explored this process at the psychological level, in the context of the relationship between the healthy and unhealthy other. Yet, the Other is necessary, for without it there can be no normal. It was the emergence of medical statistics which facilitated and reinforced the division between the normal to the abnormal and made possible the eugenic gaze (Davis, 1997).

What Hughes’ demonstrates is that the medicalised views of disability and medical practice surrounding the impaired body were integral to modernist culture, as well as

the materialist needs of capitalism, which Oliver identified. Hughes (2000) then goes on to be more specific, to provide 'a critique of medicine as culture' (557) to show how medical notions of the impaired body permeated social relations, yet appeared as if they were natural, unconnected with biomedicine. To provide this critique, Hughes analyses the concept of invalidation which he takes to have a medically derived meaning. He argues that the process of Othering is essentially a process of validating some bodies and invalidating those that do not conform to norms. One example of where this Othering occurs is the gate keeping process, explored below, where healthcare professionals both validate invalidity, by confirming eligibility for services, and invalidate validity when eligibility is denied. The dictionary definition of invalidity, Hughes tells us, suggests a 'dual meaning' of 'confinement through incapacity' and 'deficit of credibility' (558). The former meaning encapsulates the biomedical view that the *solution* to incapacity, impairment itself, is confinement and thus implying that disabled people should disengage from society. Such a view underpinned much post war social policy, for example the 1948 National Assistance Act, in which local authorities were given discretionary powers to provide services to maintain people at home or in residential care but had no mention of supporting people to go out or take a job. It also surfaces in casual remarks. For example in Begum's (1996) study of disabled women's relationships with their GPs, one participant reported that her GP had told her not to bother getting a job.

Hughes' notion of medicine as culture provides an account of how medicalised views of disability became pervasive and continue to structure perception of the impaired body. This account is perhaps more satisfactory than Oliver's in being clearer about how the medicalised view of disability permeated the further reaches of society. Hughes also takes account of the range of medical meanings of impairment and emphasises that these meanings have material consequences which contribute to the oppression of disabled people in the same way as disabling barriers.

Oliver and Hughes demonstrate how the medicalisation of disability operates upon Conrad's conceptual level but with reference to other levels, suggesting the levels intertwine. A related point is that both conceptual and institutional medicalisation of

disability are based upon biomedical interpretations of the impaired body. In turn, these interpretations influence the meanings attached to the body. But these meanings are contested within biomedical institutions and beyond. For example, some disabled people interpret their own bodily experiences as an indication of impairment and (more) problems arise when these are discounted by strangers, such as when someone with a hidden impairment gets out of a car parked in a disabled space and is challenged by passers-by, traffic wardens or other disabled people wanting to park. Perhaps more enduringly, the individual's interpretation may also be discounted by healthcare professionals. This is demonstrated by Broom & Woodward's (1996) study of people with Chronic Fatigue Syndrome (CFS) and their doctors. One of its findings was that individuals wanted their condition to be medicalised, which Broom & Woodward define as receiving a diagnosis. Without this medicalisation, the individual's symptoms were 'exacerbated' due to 'uncertainty and alienation' (371). Yet GPs were reluctant to give a diagnosis of a condition which is clinically ill defined because of what they perceived as the negative connotations of being medicalised.

### ***Medicalisation at the Institutional Level***

#### ***Gate Keeping***

I now want to consider healthcare professionals' role as gate keepers as an example of medicalisation at an institutional level. As intimated above, gate keeping describes a process whereby disabled people are 'compelled to go through a medical professional or bureaucratic agency, to get a service they require or a piece of equipment they need' (French, 1994a:109). Disabled people's experience of accessing services in this way seems to have been negative (see, for example, Davis, 2004, Finkelstein, 1990b, 1993a, Finkelstein & Stuart, 1996, French & Swain, 2000, Oliver, 1990a, Reeve, 2004). For example, it has led to 'the colonisation of disabled people's lives by a vast army of professionals' (Oliver, 1996:5, see also Blaxter, 1976, Brechan & Liddard, 1981). To some extent this has occurred and contributed to broader concerns with increasing professional involvement in people's everyday life (Illich, 1997, McKnight, 1977). Indeed, Zola (1972) has identified the growing complexity of the bureaucratic and technological systems as one of the key dynamics



of medicalisation, which ‘has led us down the path of reliance on the expert’ (487). However, Finkelstein & Stuart (1996) argue that this is a particular problem for disabled people because it reflects ‘the absence of disabled people’s real impact on the way society is structured’ (172). The point here is that due to disabling barriers, disabled people have been forced to use what are often designated ‘special services’ run by professionals in order to be able to obtain access the same social facilities as non-disabled people. This has led to disabled people’s ‘enforced dependency’ and institutionalisation (Oliver, quoted in French & Swain, 2001:737)

In this section I will consider how the different forms of professional power which surround the institution of gate keeping may shape disabled people’s experiences of accessing services via gate keepers. I will then look in more detail of two particular and very different examples of gate keeping. The first looks at a relatively new and slightly unusual form of gate keeping, the self certification claim process of Disability Living Allowance. The second will shift focus from the individual experience of gate keeping to consider how medicalisation has been enacted in the replacement of Incapacity Benefit with the Employment and Support Allowance.

The institution of gate keeping is underpinned by a number of forms of professional power. The first of these interests emerges as a result of gate keepers being agents of the state (French & Swain, 2000). As such, one of their roles is to control public spending. Hence at a political and policy level, ‘needs are defined by what public support systems are able, or prepared to afford rather than the actual barriers that disabled people face’ (Zarb, 2004:193). One implication of this is that gate keepers’ ability to respond positively to disabled people’s own assessment of their need is limited by budgetary concerns (French 1994a). This can lead to a discrepancy between the level of need that a person has to “prove” to get support, and the support which is on offer. For example, to be eligible for the highest rate of the care component of Disability Living Allowance, a claimant has to show that he needs care repeatedly during the night. Yet the amount of the Allowance is hardly enough to pay for two nights of care a week. Hence the level of disability that the claimant has to prove can be as much a rationing device as an indicator of need.

A further interest at work in the gate keeper role is professional power. The relationship between the professional and disabled person 'has never been an easy one' because the balance of power is usually skewed in the favour of the professional (French, 1994a:103) who is able to make the disabled person 'act in a ways in which they would not otherwise chosen' (Hughes & Ferguson, quoted in Abberley, 2002:239). One example of this found in the literature is an Occupational Therapist (OT) installing a toilet which was too high, notwithstanding that the disabled person had told the OT this. As a result, the disabled person had to pay for a new toilet to be installed. Such power and professional arrogance deprives disabled people of agency and undermines their expertise of living with an impairment in a disabling world (Watson, 2003). This power is also grounded in a medicalised view of disability upon which the relationship is based. Hence, disabled people are seen as 'less than equal with their non-disabled peers' (Finkelstein, 1991:5/6) and services are 'framed in terms of people's perceived deficits' (French, 1994a:108). This notion of disabled people's perceived deficits' is very similar to that of 'deficit of credibility' which Hughes (2000) identified as one medical meaning of impairment (558). It could be argued that this notion is embedded within the gate keeping role and in the related process of requiring disabled people to obtain medical validation in order to take part in a range of activities from driving, travelling to sport. One of the ironies of this is the healthcare professionals may be ill equipped to provide this validation. This is because they have neither the expertise (Oliver, 1990a) nor insight into the disabled person's everyday life necessary to make such decisions. This further undermines disabled people's agency and autonomy.

In a study of Occupational Therapists (OTs), Abberley (1995) identifies another source of professional power rooted in the way OTs create 'clients as an ideological construct' (222). Following Thompson, ideology is defined as 'creative imaginary activities', that is beliefs, which 'serve to sustain social relations which are asymmetrical with regard to the organisation of power' (222). Abberley found such a belief in the way OTs treated the client as a whole person, which involved recognition of the individuality of the client and their capacity to develop and change. Abberley argues that while seemingly humanitarian, focussing upon the capacity for self-improvement obscures the structural constraints the client faces. In

other words, the whole person is seen in isolation from the social relations, including disabling barriers, which shape the client's everyday life. From this perspective, if an OT fails to meet the goals set for the professional encounter, the client's failure to "develop and change" is blamed.

A further source of professionals' power derives from their role in defining clients' needs (Hugman, 1998). While the parameters of what constitutes need are usually set by policy makers, at the micro level it is constituted by 'the product of social interaction in given circumstances' (33). However, it is rare for this interaction to result in consensus because the social structure provides the power for dominant groups to set the terms under which needs are defined (34). Several commentators regard this professionalisation of human need to be a broad trend, started in the middle years of the 20<sup>th</sup> Century. Illich (1977) argued that this period should be known as the age of the disabling professions. One consequence of this trend is that professionals 'not only recommend what is good but actually ordain what is right' (17). Having defined need, professionals then devise methods of meeting them which require particular skills and training which cannot be gained by lay people (De Swaan, 1990). In other words, professionally defined need can only be met by those professionally trained. Thus, professionalisation is very similar to medicalisation, in that it involves defining social problems as individual ones so only individual solutions backed by professionals are possible.

In the context of disability, again Abberley's (1995) study of OT analyses with precision the consequences of professionals defining, identifying and resolving need. When asked what constituted a successful encounter with a client, a significant number of OTs said "when the goals *set by the OT* were met". In other words, what mattered were the professionals' goals, not those of the clients. Further, part of the OTs' task was to use their professional knowledge to educate the client to fit the OTs' definition of reality. Hence the disabled person's understanding of her needs was either discounted or manipulated to fit the professional's perception of need. Moreover, the task of educating the client helps to ensure the client complies with the professional's expertise, which meets another professional goal. This was seen as more important than providing equipment, despite that being the client's priority

(Abberley, 2006:241). This analysis seems to add weight to Barnes & Oliver's (1998) contention that the welfare state has resulted in exclusion, despite inclusive policy rhetoric, because services are based on professional definition of need. If 'real' client defined need is not met, the opportunities for social participation are reduced.

In addition to gate keeping being a source and demonstration of professional power, it can also be a mechanism of social control. One significant element of such control is keeping a close rein on public expenditure (French, 1994a). Yet it also involves a more subtle and insidious control. Waitzkin (1989) uses the concept of social control to highlight the relationship between the doctor/patient interaction and the social structure and to link all three levels of medicalisation in one moment. For Waitzkin, social control refers to 'mechanisms that achieve people's adherence to norms of social behaviour' (225). Ideology is one such mechanism. but Waitzkin's notion of ideology is much broader than that of Oliver's discussed above. Hence Waitzkin argues

*'What patients and doctors say when they meet reinforces their particular ideologic conceptions about social life' (223).*

Waitzkin (1989) illustrates this by considering how medical practices reinforce the 'ideologic concept' that health 'is the ability to work'. If the doctor provides a sick certificate which indicates when the patient should return to work, this reinforces both the idea that recovering from illness is normal and that, following illness, the expected social behaviour is to return to work (222). Thinking about this example in the context of disability, a doctor may not offer a sick note to a disabled patient but assume that they were *unable* to work anyway. This too would have reinforced an 'ideologic conception', in this case the contention that disabled people were incapable of working, an assumption that until recently was embedded within social relations and conceptions which constitute disability. However, it should not be assumed that the patient will act to comply with the ideologic conception: this will depend upon her agency and the factors which constrain it. In this instance the social control is subtle and contingent.

It is important to note that Waitzkin argues doctors *do not intend* to reinforce prevailing social relations or to consciously exert social control. That they do so unintentionally is the result of several factors, including the nature of medical training. Nowadays such training may stress that doctors need to take heed of psychological factors and knowledge about the social situation of the patient. However, within the medical encounter, doctors try to help patient's cope within the situation which they find themselves. Trying to do otherwise may be beyond medical power or simply inappropriate (227). The example Waitzkin gives to illustrate this is that of a patient suffering from stress due to an ongoing problem at work. It isn't within the doctor's power to change the workplace, and to advise giving up or changing work may overlook the social, personal or economic disruptions this would cause the patient. What the doctor is able to do, is advise the patient how to deal with the stress. Depending upon the issue, doctors may also act collectively to bring the matter to politicians' attention in the hope of securing appropriate social change.

Waitzkin's example highlights the social constraints which impinge upon medical encounters. However, in the context of disability and the gate keeping role, doctors may have more room for manoeuvre than Waitzkin's example suggests. As we have seen, there are many services and facilities that disabled people must access through their GP. How a GP responds to requests for required medical certification can have a significant influence on the social and physical environment in which disabled people live (Begum, 1996:2). Further, there is scope for GPs to be proactive by offering patients information about the services and benefits appropriate and available to them. This is something which the Royal College of Physicians (1996) and empirical studies have highlighted as good practice (see, for example, Blaxter, 1976, Bhakta, 2000, Locker, 1982). A cynic might argue that where GPs fail to give information is also a form of social control as it may reduce the demand for a service, thereby limiting its costs. To argue thus may seem to weaken the concept of social control because it implies that however the doctor does or doesn't act amounts to social control. However, the real value of Waitzkin's work on social control is precisely that it places any and every medical encounter within a larger social context to reveal the social relations embedded within it. While medicalisation may

individualise and depoliticise the *solutions* to social problems as discussed above, the negotiation and implementation of those solutions at the interactional levels remains political and shaped by broader social forces.

Having considered generally how social control can operate through gate keeping, I now want to look at a very particular form of gate keeping by drawing upon the work of Shildrick & Price (1996). They set about deconstructing the process of claiming Disability Living Allowance (DLA), a welfare benefit which contributes towards the cost of care and/or mobility. As post modernists, their analysis is not couched in terms of social control. Rather it is concerned with how the claim process constructs disability and how that in turn influences subjectivities, that is, how the person's internal senses of disability are mediated by the completion of the claim form.

Shildrick & Price argue that as the DLA claim process relies largely upon self certification, the form of power that operates through it is not one of 'external coercion' but of 'continuous surveillance' (104) of the impaired body by the embodied self. This is achieved by requiring the claimant to provide an account of the 'minutiae of functional capacity' which has to be used to carry out all daily tasks, including the frequency of using the toilet and the help needed to do so. In doing so, the claimant has to confront and document how his body fails to meet 'standards of normalcy' (100). While this may be true for many, it could actually be a moment of relief that someone acknowledges the minutiae of functioning which absorbs huge chunks of the day. In that situation could there be a sense of relief that this someone is asking about their daily experience? Is it helping to construct their normalcy? Or would any such relief be immediately dissipated by the tedious prospect of having to document the detail of function?

Shildrick & Price go on to argue that in responding to questions about the minutiae of functioning, disability becomes constructed and therefore understood by the claimant as a series of 'individual failings' which make them less than normal. They also argue that it creates the impaired body as an object of discourse for healthcare professionals, who have to validate what has been written on the claim form. There seems to be a discrepancy here between the information that healthcare professionals

are asked to validate and what they can know about the claimant. For example, how would a healthcare professional know how often the claimant used the toilet other than by asking them, just as the claim form does? This suggests that there is substantial scope for the professionals' judgements about the trustworthiness or deservingness of the claimant (French, 1994a). Yet this may be belied by the veneer of objectivity which is attached to medical and professional knowledge. For the claimant, this can be frustrating and be experienced as 'epistemic invalidation' (Wendell, 2003:122), a concept usually used when doctors dismiss or ignore patients' accounts of their symptoms but which seems equally useful here. Perhaps there is a further construction here, one which Shildrick & Price do not consider directly, that in seeking to establish or confirm one's disability status, one is compelled to surrender the body to the medical gaze which extends beyond the consulting room and into the furthest and most intimate reaches of everyday life.

A final point that Shildrick & Price make is that, in addition to enforcing standards of normalcy, the claim form also constructs what is normal within the bounds of disability. Claimants have to shoehorn their experience into 'the rigidly constructed parameters of disability' (104) provided by fixed questions and the limited space allowed for the answers. These parameters assume that impairment and disability are fixed and stable irrespective of the changing external and internal environments within which they are experienced. It also presumes the complexity and diversity of disability and impairment experiences can all be captured on one form. As a result, those whose experiences cannot be 'inserted' into the form are denied benefit and again have their experience invalidated.

### *Welfare to Work*

In the above discussion, a recurring theme has been that healthcare professionals are often ill-placed to comment upon the everyday experience of disabled people notwithstanding that, as gate keepers, they are called upon to do so. Interestingly, this theme is reflected in some of the research and the policy rhetoric surrounding the replacement of Incapacity Benefit with Employment and Support Allowance for new claimants from October 2008. I want to explore these reforms to consider the significance of supplementing healthcare professional gate keepers with non medical

ones. In doing so, it is important to keep in mind the relationship between rates of claims for Incapacity Benefit and the state of the economy. There are two factors here. First, the highest rates of claims for Incapacity Benefit are in areas where employment in heavy industry has declined. This is due to high levels of ill health associated with working in this type of industry and the lack of alternative employment opportunities. Second, when the economy is slack those who are sick or disabled but who can work are at the back of the job queue due to the perceived risk of hiring someone who may require time off for health problems or need adjustments to make the workplace accessible. Conversely, when there is economic prosperity and / or a labour shortage, disabled people are more likely to find work (Beatty *et al*, 2007). These economic issues are often obscured in the discourses which surround benefits policy and the claims process where the focus is upon the individual impairment or sickness. In other words the discourse is medicalised.

In his review of welfare to work policy in the 1990s, Hyde (2000) shows that eligibility for the new Incapacity Benefit focused exclusively on “functional capacity” ‘to perform work tasks, whereas its predecessor, Invalidity Benefit took account of non-medical factors such as a person’s occupation prior to becoming sick and what jobs were available locally’ (329). Accompanying this shift to a more medicalised understanding of the reasons why disabled people were unable to work (that is, due to lack of functional capacity), was an expanded gate keeping role for non medical “Personal Advisors” (formerly Job Centre employees) to supplement the medical evidence given by the claimant’s GP or equivalent. Thus, somewhat paradoxically, this more medicalised view coincided with the dilution of doctors’ role and power in determining eligibility.

This dilution continued in the government’s 2006 green paper ‘A New Deal For Welfare: Empowering People To Work’ (Secretary of State for the Department of Work and Pensions, 2006) encapsulated in the Welfare Reform Act 2007 (Fox, 2007). Ravetz’s (2006) analysis of this highlights a ‘de-coupling of health problems and medical conditions from unfitness to work’ (13). It also shows that the research underpinning the changes questioned the suitability and effectiveness of GPs as gate



keepers suggesting, for example, that they do not 'understand the importance of work for health' and that

*'For common health problems and future capacity for work, the doctors' opinion.... is unfounded, of limited value and can be counterproductive...they should simply state that there is no objective physical or mental health barrier to rehabilitation or (return to) work' (Aylward & Waddell, 2006, quoted in Ravetz, 2006:10).*

This constructs health barriers to work as being divorced from the types of work the individual has the skills to do and the availability of such work. This is contrary to the relationship between the economy and claim rates discussed above. This construction is reflected in the official guidance to healthcare professionals (Health, Work and Well-being Directorate, 2008). For example it states that in some circumstances a GP will be required to provide a 'factual' statement of incapability for work based purely on the individual's medical records. If the GP wants to express an opinion in this statement, it must be 'supported by factual evidence'. One example of what constitutes factual evidence in the guidance to GPs is the number of fits a patient has had in the past three years. However, it is not clear how the numbers of fits one has determines fitness to work. Similarly it is unclear how the GP would know this, particularly where someone has frequent fits which do not necessitate medical assistance. Indeed, this example could be seen as encouraging medicalisation by implying that the individual *should* report all fits to healthcare professionals who in turn would document them.

One interpretation of these changes to the process of medical validation of claims is that the process of claiming out of work benefits has been demedicalised. This view is supported by the 'progressive discourse' (Jolly, 2003) of policy rhetoric which is about supporting disabled people to gain employment and focusing on what people can do rather than what they cannot. However, the interpretation of demedicalisation can be challenged on three points. First, while GPs' gate keeping role seems to have been circumscribed, the Work Capability Assessment, which will be used to determine if the claimant satisfies the impairment related eligibility criteria, will nonetheless be conducted by healthcare professionals: those from a private firm contracted to the Department of Work and Pensions for this purpose. In comparison

with GPs, these professionals will have to rely more heavily on clinical information because they will not know the claimant. As has been argued, such information is unlikely to provide insight on daily life or the social and economic barriers which restrict job opportunities.

Second, any demedicalisation which has occurred has not been counterbalanced by an increased commitment to remove the environmental and social barriers disabled people encounter within the world of work (Barnes, 1999, cited in Jolly, 2003:519). On one level, Barnes's (1999) argument seems to overlook the DDA, which includes provisions to outlaw discrimination in the recruitment process and places a duty on employers to make reasonable adjustments to premises and procedures to ensure accessibility. However, his point is a deeper one - that the organisation of work around the profit motive in itself creates barriers. Further, Barnes makes the argument that many jobs now require an 'able mind' rather than an 'able body' (10) required by industrialisation, and in this context those with learning difficulties and mental health problems are most likely to be disadvantaged. A further danger here is there 'will be a refusal to acknowledge the medical realities' of impairment and the 'huge efforts [by individuals] to cope with these' (Ravetz, 2006:25) both of which create impairment related barriers to work. Yet these types of barriers have been inadequately identified. There is a risk that those experiencing these barriers may be blamed and penalised for not trying "hard enough" to get work or may be pressurised to take jobs which would be detrimental to their health. The latter may be a particular problem for those with mental health problems, where the barriers to work are perhaps more subtle: for example if someone has learnt she can only maintain good mental health by not working.

The third and final reason to be sceptical about viewing the recent benefits reforms as demedicalisation is that employment itself may become medicalised. Evidence for this can be found in the 'roll out' document (Fox, 2007). This highlights that claimants who undertake activities designed to improve health will satisfy the eligibility criteria that a work related activity must be undertaken. Similarly, a claim for the new allowance can be disqualified to penalise a claimant for 'failure to follow medical advice without good cause' (21). These requirements suggest that for

disabled people, obtaining a job could become a matter of following doctors' orders. All this resonates with Illich's (1990) argument that 'wage labour acquires therapeutic characteristics' (130), as everyday life becomes increasingly medicalised. As this happens, more people will consider themselves to be ill. Unless an increasing number of these people gained work, there would be labour shortages and substantial increases in public expenditure on benefit payments. Thus, to avoid this, work has to be seen as therapeutic as a matter of social control to avoid (further) economic crises. Similarly however, when disabled people are viewed as incapable of work via a gate keeping procedure, they become subject to 'means of social control to minimise their "cost" to society' (Barnes, Mercer & Shakespeare, 1999:57).

So far in this section, I have considered gate keeping as a form of medicalisation. This has entailed "expanding" the concept of medicalisation to consider broader issues such as how professional power and interests can constrain disabled people's lives. It could be argued therefore that medicalisation sustains and is sustained by other social forces, including welfarism and bureaucratization. Welfarism refers to social processes through which individuals receive ongoing, long-term assistance, particularly welfare payments, and the condition of being dependent upon such assistance (Prein & Buhr, 1998). In one sense, welfarism could be seen as the outcome of medicalisation, that because impairment continues to be seen through a biomedical lens the social response to it concerned with ameliorating its effects, its symptoms, rather than addressing its causes, many of which take the form of disabling social barriers which constrain disabled people. Compounding medicalisation, welfarism itself has unintended consequences, including enforced dependency on the state and its institutions (Flossy & Otto, 1998). This 'entrenches the political invisibility and powerlessness of disabled people' (Smith, 2003:346) and leads to bureaucratic intrusion into disabled people's everyday life (Oliver, 1990).

It is also possible to argue the opposite case, that medicalisation is the outcome of welfarism. This is Stone's (1984) argument, reviewed above, that it was when the state wanted to redistribute resources that it created the category of disability as a means of ensuring welfare payments only went to "the deserving poor". This

ensured the incentive to work amongst the “able bodied”, the undeserving poor was maintained. Perhaps at the end of the day it is most helpful to view both medicalisation and welfarism as two entwined forces which emerge from particular sets of political and economic forces.

As we saw at the beginning of this section, Disability Studies has been sharply critical of both medicalisation at the institutional level and the welfarist approach. Moreover, the disability movement in its many guises has campaigned with considerable success for support services which facilitate disabled people’s equal participation in social life rather than ameliorate impairment effects. It does so on the basis of claiming legally enforceable rights rather than what for politicians and the general is the ‘more comfortable’ issues of welfare needs (Sykes, 1987:176).

In this section, I have tried to unravel the complexities of medicalisation that are operating in one social institution, out of work benefits. In keeping with Conrad’s (1992) argument that instances of medicalisation do not necessarily involve a healthcare professional, I have suggested that limiting GPs role in this institution does not necessarily signal demedicalisation. I have also indicated some of the risks of a policy that demedicalises the significance of impairment or illness in shaping employment prospects. While for some disabled people the main barriers they face are disability rather than impairment related, for others the two will be interwoven or more impairment related. To address this, a policy is required that can be sensitive and responsive to impairment related differences and takes account of the DDA. Finally, I have suggested that whatever the skills or background of gate keepers, there are substantial difficulties when it comes to their assessment of disabled people’s everyday lives. Yet, unless these difficulties are confronted, the gate keeping role is likely to continue to cause problems for disabled people and their life chances.

### ***Medicalisation at the Interactional Level***

#### ***Normalising Treatment***

I now want to explore the third of Conrad’s (1992) levels of medicalisation by drawing upon Disability Studies’ debates about normalising treatment. This

treatment is what is done to the fleshy impaired body to make it literally “more normal” as defined by a ‘particular set of cultural values’ (Barnes, 2003:7). As we saw in the last chapter, biomedicine is normative, with most medical interventions aimed at normalising bodily function, something which is usually welcomed. However, a range of treatments have been problematised because they involve disabled people’s embodied differences being medicalised, that is interpreted as a medical abnormality. These differences are then treated to make the impaired body conform more closely to general bodily norms rather than what is normal for the particular disabled person concerned. The treatments that have been problematised as being normalising include the provision of artificial limbs (Hughes, 2000, Marks, 2001), physiotherapy (Begum, 1996, Johnson, 1993), rehabilitation (Barnes, 2003, Finkelstein, 1998, Oliver, 1990a, 1993) and the abortion of impaired fetuses (French & Swain, 2001).

The debate about normalising treatment seems to be rooted in Oliver’s (1990b) argument that, whilst it is appropriate that doctors treat illness or injury whether or not related to impairment, it is not appropriate for them to treat disability. Attempts to do so, he argues, reframe the collective, social problem of disability as an individual, medical one. Such reframing is a defining characteristic of medicalisation (Conrad & Schneider, 1992) and it is this to which -Oliver objects, fearing it will lead to the prioritisation of medical solutions over social ones. More pragmatically, Oliver points out as there is no cure or treatment for disability and in the face of this doctors may have a sense of powerlessness and feel pressured in to “doing something”. As a result, they may suggest normalising treatment which, while they hope will be beneficial, may not be strictly necessarily.

At one level, it is fairly straight forward to criticise this position. Oliver does not consider the difficulty of distinguishing between impairment and disability (see chapter one) or whether it should be the doctor or patient who should decide what should be treated. He appears to discount the value of treatments which, while not curative, may have positive benefits by increasing bodily comfort, functioning or both. Similarly, Oliver assumes that social remedies to disability have broadly similar benefits to those achieved through medical intervention. But this may not be

the case. For example, somebody who becomes deaf at an older age may have a cochlear implant which may, amongst other things, enable her talk to her hearing friends and family on the phone. While the social solution, getting a text phone, may potentially enable the person to keep in contact by phone, this potential may not materialise because her friends do not have such phones. Thus, the person's ability to socialise remains limited. Of course, what's significant about this example is that it is historically specific. In five years' time, technological changes may well mean that everyone, including older people, may have text phones. Hence, one benefit of Oliver's position is that it highlights that in some circumstances, medical intervention with all that it can entail is no longer the *only* option for enhancing quality of life (French, 1994a).

As I discuss below, providing Oliver's arguments are not interpreted too literally, they have other merits in the debate about normalising treatment as well. Yet this may seem unlikely when Shakespeare (2006) makes the following argument, *believing it to be controversial*:

*'I argued that a multi-level approach was needed to tackle the disability problem, one which recognised that medical intervention to treat or minimise impairment are valuable, alongside (and not replacements for) interventions at the social and structural levels' (103).*

I want to argue that this position is unassailable and that there is very little in the Disability Studies literature which suggests otherwise. Indeed it is notable recently that both Oliver (1996a) and particularly Barnes, (1996, 1999, 2003), a harsh critic of normalising treatment (French, 1994a), have repeatedly stressed that neither they nor any element of the social model of disability is against medical intervention *per se*. Rather, what they are against is the medicalisation of disability. However, I also argue that it is only because Oliver, Barnes and others have problematised normalising treatment, perhaps often in a rhetorical and didactic way, that Shakespeare's common sense position has become possible.

Shakespeare (2006) makes a further criticism of Disability Studies' approach to normalising treatment, namely that it reflects an 'unwillingness to engage with the question of impairment' (105). There is, I think, evidence of this in the lack of

hypothetical discussion about types of impairment or life situations where normalising treatment may be more or less justified. Shakespeare is also right that impairment comprises a diversity of experience, which needs to be reflected in discussions. However, similar to my argument above, in problematising normalising treatment, the Disability Studies literature provides the beginnings of a framework in which to consider whether some experiences of impairment make normalising treatment a more attractive proposition than others.

To elaborate my arguments I will now explore three interlinked criticisms made of normalising treatment. The first of these concerns is whose interests are served by this treatment. Oliver (1990b) implies that normalising treatment is not (just) about the best interests of the disabled person but also about ‘securing adherence to social norms specifically by using medical means’ which is a more general feature of medicalisation (Conrad & Schneider, 1992:242). Oliver makes this point by drawing upon Finkelstein's experiences of rehabilitation following spinal injury which involved spending ‘soul-destroying hours ... trying to approximate to able-bodied standards by “walking” with callipers and crutches’ (Finkelstein, quoted in Oliver, 1990a:54). The charge here is that the treatment was worthless because no matter what effort was expended, for Finkelstein approximating walking would always remain an inefficient means of mobility in comparison with using a wheelchair. Moreover, using a wheelchair *is normal* for someone with a complete spinal injury, so encouraging Finkelstein to walk represented an imposition of a social norm which failed to take account of Finkelstein's bodily differences. The process of doing so was soul destroying and thus risked causing psycho-emotional effects (Thomas, 1999). Elsewhere, Oliver (1996a) goes on to argue that from this interpretation, the practice of rehabilitation has to be seen as a form of social control and as such is ‘oppressive’ and an ‘abuse of human rights’ (107). This is so because it imposes on those who do not walk a value system which is at odds with their own.

For Oliver's argument to make sense, it is necessary to establish an alternative to walking which is different but of equivalent value. The social model provides this in general by positing that if social barriers are removed disabled people can have a good quality of life. More particularly, Oliver (1993, 1996a) has argued that

wheelchairs and aeroplanes are both mobility aids, the use of which requires particular environmental conditions. Finkelstein (1989) has made a similar point arguing that disabled people

*‘... are encouraged, for example, to use and highly value the PWA [person with abilities] mobility (walking) aid, shoes, while disabled people’s mobility aid, wheelchairs, are negatively valued’ (6).*

If one considers this argument solely in terms of function it is relatively easy to refute. In a thoughtfully designed building, using a wheelchair may provide a means of movement that can be equivalent to that of walking in shoes, but this is not the case in other environments, for example, in the open countryside. However, another way of looking at this is in terms of the value *for its user* in the context of his usual everyday life. For a seasoned user, a wheelchair provides a means of comfortably getting around and is taken-for-granted in the same way as a pair of shoes for a walker. Another vehicle for countering a negative evaluation of impairment has been the Disability Art Movement. This has provided both a celebration of bodily difference and the possibility of a positive identity for disabled people both individually and collectively (Swain & French, 2000). Both of these ways of thinking about impairment provide one basis upon which to resist normalising treatment. Further, neither Oliver nor Finkelstein reject rehabilitation *per se* but do criticise its current form. They argue that what is needed is a ‘systematic approach’ to enabling disabled people acquire skills to manage social barriers and to the provision of aids and necessary housing adaptations (Finkelstein, 1984).

A second set of arguments against normalising treatment concerns the pain and psycho-emotional effects that it may cause. This was hinted at above by reference to the ‘soul destroying’ hours Finkelstein spent trying to walk. It is also a point which emerges from adults accounts which reflect upon undergoing corrective medical treatment as disabled children (see, for example, Mason, 2005, Sutherland, 1981). These suggest that corrective treatments have been problematic as a result; of the ‘dismissive, patronising, punitive and unhelpful attitudes’ of healthcare professionals (Lonsdale, quoted in, French, 1994a); of not being informed about what is being



done; and the very way in which one's impaired body is touched, handled and gazed at in medical encounters. Mason describes this very movingly:

*'I was never told I was nice to look at or nice to touch, there was never any feeling of being nice, just of being odd, peculiar. It's horrible. It's taken me years and years to get over it' (quoted in Sutherland 1981:5).*

This is a reminder of the importance of understanding the detail of the embodied experience, especially as a child and/or of being repeatedly being treated as an object of medical enquiry. It could be argued that there are two issues here, one concerning the appropriateness of a particular treatment and the other concerns day to day experience of hospital routines, the attitudes of staff and the respect (or lack of it) accorded to the embodied self. So the difficult question is in what circumstances treatment is valuable despite the pain and effort it causes. As French (1994a) points out much perhaps mundane normalising treatment, such as physiotherapy to strengthen muscles or improve balance, is vital in terms of people's day to day lives, enhancing both bodily comfort and function. For many disabled people, the problem is often the lack of such treatment rather than too much. Thus the question then becomes how healthcare practice can be improved so disabled adults and children can undergo the medical interventions they judge worthwhile with the least trauma possible. This is a point I will return to in my conclusion. Here, I think Finkelstein (1990) usefully captures the tension between the hoped for benefit of treatment and the emotional and physical endurance it requires:

*'it is highly desirable to campaign and set up systems for good medical practice in relation to disabled children and adults so that we can be physically comfortable, free from pain and illness. But it seems to me that this does not imply spending ten years of ones life trying to be "normal"' (3).*

The third objection to normalising treatment, one which is strongly related to the first, concerns the consequences it has for the individual's identity. Marks (2001) argues that normalising treatment, and indeed the medical gaze itself, implies that a 'disabled person is not acceptable *as they are*' (69). She suggests that particularly in the case of young children, this can lead to feelings of insecurity and a need to psychologically withdraw from the world. Again, the underlying argument is that medical intervention can have profound psycho-emotional effects. A similar point is

made by Finkelstein (1990a) who argues that ‘obsessive concerns with normative goals’ prevent disabled people from developing ‘an independent self image’ (3).

Shakespeare (2006) too argues that there is a relationship between normalising treatment and identity, but does so to draw attention to the diversity of impairment experiences. This diversity, he speculates, gives rise to very different views on undergoing normalising treatment. One example Shakespeare gives is that people with congenital, static impairments are ‘well adjusted to their situation’ and impairment may well be an integral, positive part of identity. Therefore this group may have ‘little enthusiasm for cures’ and corrective surgery during childhood may have ‘been experienced very negatively.’ (106). By contrast, those with acute degenerative conditions may see impairment not as a characteristic of identity but as an external threat. This group may have a ‘considerable interest, even desperation for cures’ (107).

What is not clear about Shakespeare’s argument is whether the lack of enthusiasm for cures amongst those with congenital impairments emerges during childhood or in adulthood when reflecting upon childhood experiences. If the former, a significant factor might be the views and roles of parents. While a disabled child may have a positive sense of her body on the basis as she has known no other, adults may be anxious to encourage the child to be more ‘normal’, for example, to walk rather than use a wheelchair (Morris, 2002). Perhaps more likely, the views of both the parents and the child will shift and be influenced by what treatment is on offer, the child’s embodied experience and other factors going on in their lives. A critical issue then becomes the matter of consent and how the child’s voice is heard and respected.

A further problem with the identity argument is, as Shakespeare (2006) highlights, there is no straight forward relationship between impairment, disability and the adoption of identity. For example, one government backed survey in 2003 showed that 52% of those who come under the DDA definition of disability do not define themselves as disabled people (72). This raises the question of whether the identity that someone adopts is related to one’s sense of self and/or decisions about treatment. In other words, is it possible that one could refuse normalising treatment, not identify

as a disabled person, yet regard impairment is an integral to the embodied self? There would seem to be scope for empirical work to tease out the complex relations between identity and undergoing different forms of normalising treatment.

In this section I have tried to explore the way Disability Studies' scholars have problematised the medical practice of normalising treatment. While some of the arguments are didactic, a much needed discourse has been established to challenge the biomedical view that the impaired body is always in the state of being fixed. The success of this is indicated by Frank's (2006) remark that 'normalisation has a bad name in the age of disability rights' (78). This success is both timely and necessary to provide ballast against broader cultural pressure to continuously improve the appearance and function of the now malleable body (Shilling, 2003) and where the 'judgement of social worth has become thoroughly aestheticised' (Hughes, 2000:560).

There is a further problem to note about the Disability Studies' debate on normalising treatment: there has been little recognition for disabled people's agency and the way they engage with the complexities of normalising treatment (but see, for example, Aspinall, 2006, Sullivan Sanford, 2006). As with much of the early writings on medicalisation, Oliver (1993) assumes that individuals are passive "victims" of medical care (Broom & Woodward 1996). Perhaps this is why there has been so little discussion about how to ensure disabled people, including disabled children, can be enabled to make fully informed choices about medical interventions *and* non medical alternatives. This is all the more necessary given that some healthcare professionals may be sceptical that disabled people can enjoy a good quality of life and thus over emphasise the potential benefits of the intended treatment (Miller, 2006). Zola's (1991) work is useful in this context, as he suggests that strategies should be devised to empower patients, for example by encouraging patients to prepare for consultations and through the provision of advocacy services.

## **Conclusion**

While most people, including disabled people, value timely and appropriate medical interventions, this chapter has explored how medicalised views of disability have

also placed a number of constraints upon disabled people both as patients and citizens. Disability Studies scholars have used the concept of medicalisation to highlight and challenge these constraints. Some scholars have argued that ongoing medicalisation diverts resources and distracts attention from the political project of barrier removal. For example, Oliver (1999) argues that public resources invested in individual interventions such as rehabilitation give poor returns compared with that channelled into making the environment accessible. This is because individual interventions only benefit those privileged enough to access them, whereas removing barriers helps large groups of disabled people as well as older people and those with young children. However, at a policy and political level, it is not clear if there is a direct substitution of resources being allocated to individually based interventions rather than collective ones. In this context then, Shakespeare's (2006) argument that there needs to be multi-level solutions to disability and impairment is perhaps more radical, demanding more money for most types of solutions.

Further, in some ways Oliver's argument overlooks the very real gains that the disability movement has made in the development of resourced backed policy that transfers power from gate keeping professionals to disabled people. The movement's lobbying, consulting and promotion on independent living is a key example of this. Through the vehicle of Direct Payments, many disabled people have gained substantial control over their day to day lives and there is hope the government's Personalisation agenda will expand this.

Finally, with the exception of Begum (1996), little consideration seems to have been given to if and how healthcare professionals' role as gate keepers infringes upon the doctor-patient relationship more generally. Similarly, there has been no exploration of how medicalised interpretations of the impaired body influence disabled people's relationship between the embodied self and the impaired body. These are issues that will be discussed in the analysis of my data in chapters six and eight. Nonetheless within the academy the greatest challenge is to envision the impaired body *outwith* medicalised views

## CHAPTER 5

### Methodology

This chapter aims to provide an account of the design and practice of the research upon which this thesis is based. It will guide the reader through the choices made at each stage, the reasoning behind them and their epistemological and practical implications. It will also compare and contrast what I set out to do with what I actually did. All this will be placed in the context of wider debates about social research methodology.

It is generally recognised that, while the elements of research design suggest a linear process from the setting of the research question through to data analysis and presentation, in practice the process is cyclical (Blaike, 2003) and iterative (Bechofer & Patterson, 2000). This was my experience as I kept revisiting and revising earlier decisions in the light of experience and the development of my thinking. In addition, my research had two beginnings. The completion of five pilot interviews coincided with the start of an eighteen month suspension of my PhD on the grounds of ill health. The outcome of both these events resulted in significant changes to my research design. All this created dilemmas for structuring this chapter. In the end, a chronological approach has been used. There are two exceptions to this: first, in the *Theoretical Approach* section, I discuss how my thinking developed after the first and second beginning, and second, in the *Conducting the Interviews* section, I reflect upon both the pilot and main interviews.

An enduring component of my research design and practice has been reflexivity, which ‘refers to the researcher’s conscious self-understanding of the research process’ (Hammersley & Atkinson quoted in Wainwright, 1997:11). I have used my diverse experiences as a disabled person, a former activist and worker in disabled people’s organisations as a resource (Stanley & Wise, 1993) at each stage of the research process. In addition I have paid attention to how the enactment of my impairment and the disabling barriers I faced influenced my research practice. Reflexivity will also be the means through which the validity of the research will be

established: by highlighting the ways in which my embodied self and my biography have moulded the research process, the reader may judge the influence these had on data generation and analysis (Seale, 1999).

## ***First Beginnings***

### ***Research Design***

If a research design is a plan ‘for getting from here to there’ (Yin, quoted in Blaikie, 2003:35) then its first stage is to specify the location of ‘there’ by devising a research question. In this regard, the terms of my scholarship gave much room for manoeuvre. It set the topic as disability and health and it made sense that the geographical boundary of any field work should be Edinburgh and the Lothians, the area covered by ECAS, the disability charity which funded the scholarship. ECAS hopes that any relevant research findings will enable it to lobby for better health care for disabled people.

Finding a focus for the research was difficult because my interests were broad and both theoretical and empirical. I was fascinated by the apparent paradox that, although disabled people are often frequent users of the NHS, neither the social model of disability nor the disability movement had much to say about health or the problems disabled people experience when using the NHS (DeJong & Basnett, 2001, Begum, 1996). This suggested that some sort of exploratory research would be appropriate, with a research question that would enable disabled participants to identify and discuss the health care issues which they deemed important rather than what *I thought* was important. My task would then be to consider the implications of disabled people’s health care experiences for the theoretical understanding of disability as well as to generate useful information about health care experiences for ECAS.

At this point, I followed Blaikie’s (2003) advice and brainstormed all possible questions. The question which emerged from this process was

“What social factors influence disabled people’s experiences of using Primary Health Care in Edinburgh and the Lothians?”

“Social factors” is a somewhat imprecise concept but signals that the study is sociological rather than medical and focused upon the disability and impairment related issues that influence disabled people’s experiences of using Primary Health Care (PHC). The decision to concentrate on PHC reflected the shift of resources from hospital based care to primary health care which has occurred since the 1980s (Klein, 2001) and the fact that 90% of all NHS contact is at this level (Scottish Consumer Council, 2001). PHC incorporates a range of services from district nursing to community based rehabilitation. Considering if and how disabled people use a range of services would facilitate exploration of how disabled people build up the support networks they need and the ease or otherwise of accessing different services. This would build an element of comparison into the study which is an essential part of good research design (Bechofer & Paterson, 2000).

Having devised a broad research question, this was broken down into three main areas of interest and in each of these secondary research questions were generated. The three areas were:

- **Experiencing Impairment** - One of my interests was to understand the everyday experience of impairment and if and how this influences health care encounters. As part of this I was also interested in how people differentiated impairment, illness, disability and health. I was hoping that by getting people talking about their health care experiences I would be able to explore these relationships and gain a greater understanding of how people experienced impairment and how it is embodied.
- **Managing NHS Use** - My second area of interest was how disabled people use the NHS. Do disabled people feel that the support and care they receive from primary health care meets their needs? How do disabled people get or negotiate the support they need? Many disabled people say that their GPs know little or nothing about their condition (Jessop, 1996). What implications does this have for the doctor-patient relationship and the quality of care that the disabled person receives? The Expert Patient Initiative (Department of Health, 2001) aims to increase disabled people’s skills and confidence in managing their own condition and encourages professionals to respect patients’ choices

when deciding upon treatment regimes. To what extent were disabled people already expert patients? What was the basis of this expertise? How was it acquired?

- **Access and Barriers** - One of the social factors likely to affect disabled people's use of health care is disability access issues, for example the difficulty of finding a dentist willing to treat a wheelchair user in his own chair if he was unable to transfer to the regular dentist chair. Here, my interest was not in documenting the range of barriers faced but how people dealt with these barriers in the context of the health care. Does dealing with such issues have an emotional or psychological cost for some? Does it impact on the health care relationship? What disability and non disability factors influence how people deal with barriers? Further, the relatively recent Disability Discrimination Acts (DDA) require health care providers (amongst others) to take reasonable adjustments to ensure its services are accessible. These adjustments must be made to any policy, physical barrier, practice or procedure which might otherwise lead to a disabled person being treated less fairly than a non-disabled person. Is this proving an effective framework to tackle access issues? What has helped or hindered the implementation process?

At this stage then, my research was aiming to be exploratory and to generate data which would enable me to describe a range of factors influencing the way disabled people used the NHS in Edinburgh.

### *Theoretical Approach*

At this stage then, my research was aiming to be exploratory, to generate data which would enable me to describe a range of factors influencing the way disabled people used the NHS in Edinburgh. Implicit in this aim is an interpretation of health care encounters which is limited to using the NHS, to those encounters that occur in clinical settings. Consequently, the factors influencing more informal encounters are excluded. These informal encounters include health promotion campaigns, searching for health related information on the internet or medical advice given opportunistically, for example, advice given by district nurse when helping with a routine daily living task. It also excludes health care encounters what are a result of



medicalisation at the institutional level (see chapter four), for example, when a disabled person has to have their impairment verified for bureaucratic purposes by someone other than a healthcare professional.

Focussing upon formal health care encounters runs the risk of overlooking the more subtle and insidious health related influences on disabled people's experience of disability and impairment in general and their experience of healthcare in particular. It rules out a Foucauldian analysis of medical knowledge/power and its role in shaping subjectivities. However, I believe that these risks can be justified on three grounds. The first of these is pragmatism. As mentioned above, ECAS was keen to use my research findings to lobby for improvements in healthcare practice. I felt this keenness would be best served by looking at easily definable health care encounters where the potential for effecting relatively small but significant changes might be greatest. The focus on clinical encounters was also pragmatic insofar as it narrowed and clarified my research interest, making the research process more manageable. It also facilitated a more in depth analysis, the importance of which is discussed below.

The second ground for focusing on clinical encounters was that, as we saw in the previous chapters, the Disability Studies' literature is skewed towards understanding disability and impairment outwith the formal healthcare context. Within this literature there are a number of useful, small scale studies of disabled people's experience of healthcare, for example, Begum (1996), Lonsdale (1994) and Thomas (1997 & 2001). However, these all focus upon disabled women's experiences and are limited to a particular type of healthcare setting: for example, Begum's study looks at relationships between women and GPs and Thomas (2001) at the use of maternity services. Moreover, these studies do little to draw out the implications of disabled people's clinical encounters for the theoretical understanding of disability and impairment. My research aims to build upon these studies by looking at disabled men's experiences as well as disabled women's across a range of healthcare settings and consider what can be learnt about impairment as a social phenomenon by looking at the experience of healthcare.

My third justification for focusing upon formal healthcare settings, one that became apparent in retrospect, is that it does not preclude exploration of the influence of health care encounters in the moments prior to, or after, clinical encounters. This will become apparent in chapters six to eight where the data analysis is presented. Here we shall see, for example, how rehabilitation encounters influence the daily enactment and “doing” of impairment, how the absence of clinical encounters influences the self management of impairment and increases disabled people’s appreciation of impairment solidarity, that is sharing healthcare and bodily experiences when attending meetings of impairment specific support groups. Indeed, I would argue that one of the significant findings of my research is that getting disabled people to talk about health care encounters is a useful way of exploring disabled people’s experience of impairment. This suggests that one of the contexts in which disabled people become aware of their impaired body is healthcare settings.

Having decided upon my research questions, my next task was to clarify my ontological and epistemological stance. This was a necessary prelude to deciding which research methods to use because each type of method is predicated upon a set of philosophical beliefs about the nature of the social world and what constitutes evidence or knowledge of it (Hughes & Sharrock, 1990).

At this stage of my research, I was clearer about the theoretical approaches I didn’t want to adopt than the one I did. Within Disability Studies there has been significant criticism of much disability research, on the grounds that it has failed to explore disabled peoples’ viewpoint, failed to see disability as a political issue and failed to make any impact on disabled people’s way of life (Oliver, 2003). As a corrective, Oliver (1996d) argued that disability research should be emancipatory and rooted theoretically in the social model of disability with its materialist underpinning. While sympathetic to some of these arguments, I felt the limitations of the social model (see chapter one) would hamper exploration of my secondary research questions. For example, the social model has little to say about the embodied experience of impairment, one of my interests. I also wanted to be able to draw upon a range of approaches in order to explain ‘what was going on’ in participants’ accounts of their experiences. Having said all this, I nonetheless wanted to draw

upon some of the social model's key insights, namely that there is a very strong and significant socially created element to disability and that this often takes the form of barriers.

This suggested that I should take an eclectic approach to theory, drawing ideas from a range of traditions at different points in the research process. Such an approach requires 'active engagement' to think through the implications of different theories and their underlying epistemology and ontology to ensure they are philosophically compatible (Mason, 2002:15). So, for example, a positivist approach which suggests that there is an objective truth which can be revealed through a disinterested observer using quantitative methods would be incompatible with a post modernist one which suggests people's social experiences are constructed through language and discourse. This active engagement will continue throughout this chapter and the three which follow. However, at this stage, it was useful to have a theoretical starting point to guide my research design. For this purpose, I adopted a broad interactionist framework. A key interactionist concern is how human beings assign meaning to all aspects of the social world (Plummer, 2000). This process of assigning meaning is negotiated through interaction and is always in a state of flux. It is through interaction that the social world is continually constructed within everyday life. One of the advantages of interactionism is that it assumes human beings are active agents, an assumption which I will make of disabled people. This challenges cultural stereotypes of disabled people as pathetic and helpless (Shakespeare, 1994). Also, in keeping with my research interest in access and barriers, it will enable me to explore access as something which has to be handled through social interaction. Further, as we have seen (chapter two) the meanings of disability, impairment and health are contested. Understanding the meanings that research participants give to these concepts and if and how these influences health care encounters will be a key task of the research.

However, one criticism levied at interactionism as it has been applied in Medical Sociology studies of chronic illness, is that insufficient attention is paid to the role of social structures (Thomas, 2007, Watson, 1998). Following my *Second Beginnings* when considering whether to use an autoethnography (see below), I came across the

work of feminist Dorothy Smith (1988) who offered a way round this problem. Smith argues that women are ‘knowers’ of their own everyday experiences. Rather than the researcher producing knowledge by interpreting or finding meaning in this social interaction, Smith argues that researchers should analyse women’s reported experiences in order to make transparent how the relationships of production and ‘relationships of ruling’ shape everyday experience (4). Critical here is the idea that women’s everyday experience doesn’t just happen but is produced through political and social relationships. As Smith puts it:

*‘the everyday world ... the matrix of our experience, is organised by relations tying it into larger processes in the world as well as by locally organised practices.’ (10)*

From this point of view, social theory should emerge from understanding women’s everyday experience in its social context. This avoids theory being imposed upon women’s experience, with any mismatch between the two being explained by “moulding” women’s experience to theory, for example, by using the Marxist concept of “false consciousness”.

A further idea in Smith’s standpoint theory, and one which flows from the first, is the emphasis she places upon starting from women’s *subjective* experiences. Doing so is to recognise and explore the role subjective experience plays in relationships between the individual and society and hence in the way in which society operates. Again this contrasts with the positivists’ orthodoxy, in which the subjects of research are cast as objects, to be observed and interpreted. From Smith’s view point, to ground research in subjective experience is to start from ‘the body, in the place in which it is’ (82).

Starting with the body is particularly appropriate for my work given the need to incorporate embodiment in the understanding of disability and impairment (see chapter one). To quite literally ‘flesh out’ Smith’s approach I intend to use the concept of the lived body. One of the great strengths of the concept of the lived body is that it incorporates understanding of the subjective “feeling” body as it is experienced by the individual in the context of everyday life. This is particularly important in relation to understanding disabled people’s experiences, given that

biomedicine has dominated interpretations of the impaired body (see chapter three). A focus on the lived bodies of disabled people is a means of challenging this domination.

Theoretically speaking, the lived body has been closely associated with phenomenology, which is a descriptive science of “existential beginning” (Williams & Bendelow, 1998) and with the writings of Merleau-Ponty. It refers to the ‘facticity’ of the body, which is real and exists prior to any analysis or reflection upon it and which is always experienced in relation to a given environment (Merleau-Ponty, 2004). Thus the body is the ground level of all knowledge, we come to know the world through our bodies (Hughes & Paterson, 1999). All higher levels of other knowledge are built upon the lived body which is ‘the acquired dialectical soil upon which a higher “formation” is accomplished’ (Merleau-Ponty, quoted in Baldwin, 2004:8).

### *Data Generation*

My next task was to consider what methods I would use to generate the data which would at be the core of my research. Using qualitative methods seemed appropriate. This is because such methods are designed to elicit ‘in-depth understanding of the meanings and “definitions of the situation” presented by informants’ (Wainright, 1997:2). What I wanted to discover was how disabled people defined their situation when using the NHS, if and how they felt disability or impairment played a part in that definition.

A number of different techniques can be used to collect data which reveals participants’ meanings and definitions of situations. For example, I considered running focus groups which might have allowed participants to ‘think out loud’ and draw out from each other how disability and impairment issues influence healthcare use. However a concern here was confidentiality: people may have felt uncomfortable about revealing health and impairment matters in a group of strangers who may have had little in common with each other. Further, I was sensitive to the fact that disabled people often experience invasions of their privacy in order to access services or to deal with comments from strangers. I did not want to add to

that. It was for similar reasons that I ruled out using ethnographic methods, despite the fact that this would have given first hand access to relationships between disabled people and healthcare professionals. There was also a practical problem with this, in that there is no obvious healthcare setting in which one will necessarily or only observe disabled patients.

Having ruled out focus groups and ethnographic observation, I decided to generate data through one-to-one interviews. Qualitative interviews are informal and semi structured and this makes them suited to exploring lived experience and subjectivity, which is my aim. Using a topic guide as opposed to an interview schedule can help to ensure the interview covers relevant areas of interest yet remain sufficiently flexible to follow topics that participants feel important (Kvale, 1996, Mason, 2002).

What then would be the relationship between the data generated through the interviews and the aspect of the social world in which the research was interested? This is essentially an ontological question, the answer to which has to be informed by my interactionist starting point. From this point of view, there are multiple realities and the meaning attributed to each is always negotiated. Therefore, semi structured interviews are best conceived as a collaborative process through which significant moments of the past are reconstructed. These reconstructions are filtered through participants' memories and reflections as prompted by the researcher's questions, demeanour, as well as the circumstances in which the interview take place. Thus the data derived from these interviews will be highly contingent and the knowledge produced is situational. As a result, the research process needs to be made as transparent as possible so the reader can judge the degree to which the research process itself has mediated the relationship between the data and the events or meanings described therein (Mason, 2002).

### *Criteria for Inclusion in the Research*

A vital part of qualitative research process is sampling and selection, that is, the principles and procedures devised to determine the population from which to recruit participants, how to select participants from that group and how many participants to

select and interview (Mason, 2003). In this section I will consider the first of these, the criteria I used to recruit participants for the study.

The population from which I would find evidence to explore my research question was disabled people. Identifying this population was beset with difficulties. Most official sources of statistics on disabled people reflect the purpose for which the data was collected and there is no single definition of a “disabled person” which suits the needs of all those who gather disability statistics. Moreover, whatever definition used, those that identify themselves as a disabled people are not necessarily the same group that those collecting statistics had in mind. This point is illustrated by a survey that suggested that only 52% of those deemed to meet the criteria of a disabled person in the DDA actually identified them self as a disabled person (Shakespeare, 2006).

In some ways, I was able to sidestep these definitional problems by adopting a social model of disability perspective. From that perspective, a disabled person is anyone who identifies them self as such on the basis of experiencing disabling barriers. In the context of my research this self definition approach made sense on two grounds. First, given that the research aim was to learn about disabled people experience of healthcare, I needed to talk to who used the category disability to make sense of some of their experiences of healthcare. Second, I felt that I had no authority or justification for overriding either a potential participant’s claim to be disabled or to impose a definition of disabled person on someone who was not comfortable as identifying her self as such.

Having adopting a social model perspective as the starting point in defining my sample population, I then limited that population by establishing three further criteria for selecting participants for the study. These were:

- Self identify as having a physical impairment
- Be a resident or work in Edinburgh or the Lothians
- Be aged between 18 and 64

Each of these criteria was influenced by the funding of the Project: ECAS works with younger people with physical impairments in Edinburgh and the Lothians. To ensure the research findings were relevant to ECAS, it made sense to focus upon the experiences of its client group. More pragmatically, as I do not drive, travelling to interviews outwith Lothians, or getting participants to come to me, would have been difficult and expensive. There was another reason for the age criterion. Rightly or wrongly, in terms of health policy, older people and disabled people are often seen as distinct groups. A further question here is the definition of 'disabled person'. There is a plethora of 'official' definitions for the purpose of determining entitlement to benefits and services. However, what matters for my purposes is that people define *themselves* as disabled and want to talk about how their impairment and disability impact upon their healthcare experience.

### ***Recruitment of Participants***

The strategy for recruitment of participants was through disability networks including:

- Impairment specific groups such as the Multiple Sclerosis Society
- Specialist disability Housing Associations
- Personal contacts

It was possible to foresee a number of drawbacks to this approach. The first was that many disabled people were not in touch with these networks. Arguably, these people would be particularly isolated and perhaps have greater reliance on the NHS, particularly for information about services and benefits. Therefore it was planned to place a small advert in a local paper through a contact with ECAS who funded the Project. Second, having to rely upon people to volunteer to be interviewed made it difficult to ensure a diverse group of participants in terms of gender, race, class and impairment type. Yet this was vital, not least to enable me to compare disabled people's experience so as to be able to understand how different facets of people's identity influence their health care encounters. Therefore I planned to contact as many networks as possible.



This method of recruiting participants meant that I could make no claim that they were in any sense representative of the sample population (see above). Rather, the aim was that taken as a group, participants' hinted at the range and diversity of experiences to be found in the sample population.

### *Ethical Issues*

As my research involved health issues, I applied for ethical approval through The Lothian Research Ethics Committee (LREC). Approval was granted subject to two stipulations:

- That all research documents were made available in accessible formats
- That participants should advise their GP of their involvement in the Project

To comply with the first stipulation, all information about the Project was amended to indicate that it was available in other formats on request. The second stipulation appeared to be based on a medical model interpretation of disabled people as vulnerable, particularly when talking about health issues. I found this disconcerting and at odds with the tenor of the research<sup>4</sup>. Thinking it through, however, I realised that participants could be given *the choice* of whether or not to contact their GP. At the beginning of each interview, I told the participant that it was considered good research practice to inform their GP about taking part in the Project. The participant was then given a pro forma letter from me to the GP along with a blank stamped envelope. I explained that if the participant wanted to tell her GP, all she need do was write her name and address on the letter and then post it in the envelope provided. This procedure meant I didn't have to know if the participant sent the letter. Similarly I didn't need to know any details about their GP. In this way participant's choice was maximised and the fear and risk of breaching confidentiality

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<sup>4</sup> The Project's Information leaflet stated I was a disabled researcher. It is not clear whether the Committee overlooked this or had a reason for believing that, unlike my participants, I was not vulnerable.

was minimised. One participant queried the letter but appeared satisfied with my explanation. Another mentioned being undecided about sending it, fearing it might influence how the GP would respond to her request for proof of disability for another matter.

In addition, the Ethics Committee queried why no consideration had been given to the protection of participants from “vulnerable groups” that is, people with learning difficulties and mental health issues. In response, I gave the reasons why the research focused on people with physical impairments. These reasons included the fact that healthcare literature and policy rarely focuses upon the inclusive category ‘disabled people’. Rather, it breaks the category down into three groups: people with learning difficulties, mental health issues and physical impairment. If I used an inclusive category there was a risk my project would only scratch the surface of the main issue for each group. Further, substantive changes in the research protocol would have been necessary to ensure the access needs of participants with learning difficulties and mental health issues would be adequately met. Having made these points, I acknowledged that people’s experiences do not fit neatly into these categories: for example some people with physical impairments may also experience mental health issues. Therefore I discussed what I would do to ‘actively consider’ inclusion of those who had experience of physical impairments and other forms of impairment. In the event, all research participants had physical impairments, while two also had learning difficulties and five also had mental health issues.

### *Role of Researcher*

The final aspect of my research design I had to decided upon was my role as researcher. To do this required consideration of debates about the nature and production of knowledge. Until the early 1970s, the positivist paradigm underpinned most social research. Simply stated, this paradigm posited that there were social facts “out there” which exist independently of any particular person or social situation. These ‘facts’ can become knowable through research practices deliberately modelled upon those used for scientific inquiry into the workings of the natural world. Crucial to these is the injunction that researchers adopt an objective stance and employ various methods to ensure the data are a ‘truthful’ representation of the

phenomenon being studied. From this point of view, sociological knowledge is produced by those within the academy and, as such, is privileged (Stanley & Wise, 1993). This view, along with the positivist paradigm itself, has been increasingly challenged.

One aspect of this challenge has been to consider the implications which arise when significant aspects of a researcher's life experience resemble those of the research participants. Some feminists and proponents of Black studies have argued that it is *only* when a researcher does have similar life experience to participants that the situation of women or Black people can be understood. Merton (1972) has dubbed this the "Insider Doctrine":

*'...as a matter of epistemological principle, particular groups in society in particular moments of history lay claim to having monopolistic access to certain kinds of knowledge. Taken to its logical extreme, as it is by some, this means "you have to be one in order to understand one"' (15).*

This implies that knowledge is situated and partial, that who we are influences the knowledge we can produce. Yet on the other hand - or perhaps at the same time - the feminist writer Du Bois warns of the dangers of being an insider:

*'The closer our subject matter to our own life experience, the more we can probably expect our own beliefs about the world to enter into and shape our work - to influence the very questions we pose, our conception of how to approach those questions, and the interpretations we generate from our findings' (quoted in Reay 1996:62).*

The concern here is that being an insider will *unduly* influence what we can know, not least because the researcher will *assume* s/he knows certain things about the insider rather than ask about these things. The question that I needed to address was whether being a disabled researcher researching disability would be a help, a hindrance or both?

Interestingly, despite considerable debate within Disability Studies about the appropriate purpose of disability research, very little has been said about the advantages or otherwise of being an insider (but see Branfield, 1998). In one sense, this is consistent with the social model that regards barriers as features of a

materialist environment that can be identified by anyone who looks for them. Hence Oliver (2003) has argued ‘the crucial issue in developing more useful and less alienating research is that of control not experience’ (9). For Oliver, research that it is useful is emancipatory, that is the research process is used as a political education tool, enabling research participants to name the difficulties they face as oppression and to learn that change is possible through political struggle (Oliver, 1996c). This requires that disabled people must have control over the production of research, the topics to be researched, the methods used and so forth. So being an insider is vital in directing the production of disability knowledge but not in the day to day process of its collection. Finkelstein (1999a) argues this is necessarily so because the very barriers that need to be researched hamper or prevent disabled researchers from conducting research. In other words, ensuring that disabled people are in control of research production is what would be considered, under the DDA, a reasonable adjustment to overcome the disabling barriers inherent in research practice. This line of argument about control is also a challenge to the idea that knowledge production is limited to those within the academy (Stanley & Wise, 1993). However, it overlooks the experience of the many disabled researchers who do negotiate and or engage with those barriers which emerge from the doing of research. This is a point I will pick up below.

Oliver (1996c) goes on to make a further demand on disability researchers, namely that they commit to taking the side of disabled people. This feeds into Becker’s (1967) classic argument that it is not possible to do research “uncontaminated” by the researcher’s personal and political sympathies. Therefore the question was not should researchers take sides, but whose side should they take?

But what if taking sides diminishes the credibility of the research which is derived from the presentation of evidence and reasoned argument rather than the promotion of a particular set of interests? For Becker, this problem could be solved by using ‘our [research] techniques impartially enough that a belief to which we are especially sympathetic could be proved untrue’ (246). This is interesting on a number of counts. First, it implies that while researchers may nominally take sides, this should not be allowed to compromise a commitment to the presentation of a fair and faithful

representation of the research findings. It is this that leads Hammersley (2000) to caution against a radical reading of Becker, which would impute that Becker thought an objective point of view impossible, or at least not worth striving for. Second, Becker places faith in the methodology of social research as a means to counter bias although concedes that methodologies tell ‘us how to guard against error, but they do not tell us how to make sure that we will use all the safeguards available to us’ (246). A third point, which underlies the first two, is that Becker’s argument implies that there is a ‘truth’ or at least a reality “out there” and a means through which one can strive to represent or understand it, albeit partially and at a given moment in time.

All this suggests that personal integrity on the part of the researcher is as important as methodology, and both can help the researcher to negotiate the tension which exists between gaining the fullest possible understanding of the phenomena being researched and commitment to its subjects. Gouldner (1973) makes a similar point in his critique of Becker’s work:

*‘A partisanship that is set within the framework of a larger humanistic understanding is quite different from one devoid of it. This is one difference between the merely political partisanship of daily involvement, and the more reflexive and tempered partisanship which may well be such objectivity of which we are capable’ (53).*

What I think is being suggested here is that one has a commitment to giving voice to “the underdog” but that there should be a similar commitment to understanding the broader context in which the underdog is situated. To do this, Gouldner argues, one has to be explicit about which side one is on, as Becker suggests, but also to go further than this by examining the values which lead one to take the side one does and to assess the consequences of doing so. Doing so requires a researcher to be explicit about why she has taken a particular viewpoint. This makes it easier for others to evaluate and comment upon the research, which is a vital part of the academic tradition. If a researcher asserts rather than argues the case for his/her viewpoint, critics may be accused of being against the particular group to which the researcher is committed and real debate may be stifled (Hammersley, 2000).

One final difficulty which relates both to being committed and to being an insider is that the oppressed group with whom the researcher sides may be assumed to be homogenous and have similar interests. Hence the researcher may not capture the complexity and the diversity of those being studied, and so vital information about how oppression operates or how people in different situations resist oppression may be lost. To be an effective academic researcher and to be committed, it seems one has to be open and ready for one's own theoretical conceptions and personal assumptions to be challenged. If such a challenge occurs, one has to be ready to engage with the political consequences (Finch, 1984).

The arguments reviewed above suggest that a researcher's commitment to a particular group has the *potential* to compromise her capacity to gain the fullest possible understanding of a social problem. However, the same point could be made about a commitment to being a detached observer. In that case, one's values and life experience may limit or colour one's understanding of the problem without being aware of this. In both cases, the researcher's integrity and commitment to enhancing social understanding can act to counter biases.

So what does all this mean for my role in my research? In several senses, I cannot but be an insider, given my biography and experience of disability. Further, it would be likely that participants would perceive me as an insider. Yet I am persuaded by the argument that the futile struggle to be objective is nonetheless worth making. It will enable me to learn from the diversity of participants' experiences and endeavour to understand them by placing them in a social context.

Having decided not to be actively committed in the sense Oliver suggests, there still remain two related questions: how should I handle my insider status and what form of relationship should I strive to have with participants? With regard to the relationship between the researcher and participant, Oakley (1997) advocates that there is 'no intimacy without reciprocity' (49). This suggests that the researcher has to be open and willing to invest something of herself into the interview. Oakley goes on to note that this is one means by which to establish rapport which is as much about manipulating the participant to provide "good data" as it is about establishing a

genuine sympathetic relationship. There seems to be little consensus or indeed advice about how to achieve this and much depends upon the interviewer's personality and the degree of involvement with which she feels comfortable.

Within Disability Studies, many have called for disabled people to be in control but few have explored how this can be achieved in terms of the researcher/participant relationship (Barnes, Mercer & Shakespeare, 2000). There are two exceptions to this. Shakespeare (1996), while expressing scepticism at the emancipatory project, nonetheless describes his attempts to reduce the power imbalance between researcher and participant. For example, he explains to participants the research aims, asks if they want to read and comment upon interview transcripts and indicates a willingness to answer personal questions. This ensures that the research process reflects and acknowledges that the disabled person, rather than the researcher, is the expert. This challenges traditional research practice as well as commonly held assumptions that professionals, rather than disabled people, are expert in disability.

Drawing on feminist literature and reflecting the Du Bois point quoted above, Vernon (1996) argues that the closer the researcher is to the researched in terms of social position, the more likely the researcher's beliefs and values are to influence the research. Hence

*'reflexivity, the examination of the ways in which the researcher's own identity and values affect the data gathered and the pictures of the social world produced, is a critical exercise for those researching the experience of oppression, particularly to ensure the avoidance of colluding with the established hegemony' (159).*

I think such reflexivity is also needed to help a researcher who is an insider trying to know other insiders unravel the multiple and sometimes conflicting interests she has in the research. In my own case, as a disabled woman researching disability issues, I am not only a researcher but also the subject and object of my research. This requires a certain self-awareness so as to be clear from which of these interests or positions one is acting.

There is one further reason to be reflexive which comes from Finkelstein's (1999) observation that every disabled researcher faces the paradoxical situation of having

to engage and negotiate with the very barriers that she is researching. My argument, however, is that this is an excellent learning opportunity. Through being reflexive at each and every stage of the research process, it becomes possible to observe, analyse and document how the minutiae of disability and impairment influence the process. This makes it possible to give an embodied account of the doing of research, something to which I will now turn.

## ***Second Beginnings***

My second beginning comprised two events: considering how to use my personal experience of health care encounters and reflecting upon and analysing five pilot interviews which I conducted immediately before suspending my PhD. Together these events led me to make substantial changes to my research design.

### ***Personal Experience***

Returning to the research after eighteen months of numerous health care encounters, I questioned whether and how I wanted to draw upon these in my work. If there are multiple realities and, as Smith (1988) argued, all knowledge is partial (see above), then researchers' subjective experience can also be analysed and contribute to the story that sociologists can tell about what it is to be human and live in a particular society.

Autoethnography is one means of exploiting researchers' experience. Although autoethnography has been variously defined and takes many forms (Humphries, 2005), most definitions and autoethnographical texts display two common features. The first of these is that these texts situate the self at the intersection between personal struggles and the public issues of social structure (Church, 1995:2) or connect the 'personal to the cultural' (Ellis & Bochner, 2000:739). The aim is then 'to learn from the one about the many' (Church, quoted in Sparkes, 2002:216).

The second feature of autoethnography is that writing from the subjective requires researchers to convey not only rational thoughts about experience but also its emotional and bodily textures and the ever shifting senses of self. To do this, Ronai suggests using a 'layered account' which she defines as



*‘...a narrative form designed to loosely represent to, as well as produce for, the reader, a continuous dialectic of experience, emerging from the multitude of reflexive voices’ [of the writer] (Ronai, quoted in Neville-Jan, 2004:116).’*

I was excited by the prospect of writing a ‘layered’ account of my experience. Through personal writing, I had become convinced of the importance of bodily detail, the otherwise mundane, in the understanding of disability and impairment in healthcare contexts. I had also become interested in the emotional dimensions of impairment. I worried these things may not be captured in a one hour interview with participants, and this made autoethnography all the more appealing. But I had concerns too. Would it lead to a privileging of my experience over that of participants? Would it perpetuate the ‘tragic but brave’ stereotypes of disability which abound in literature and the media (Couser, 2000)? Would I feel uncomfortable blurring the line between my public and private embodied self? So should I write “for my eyes only”, so as to prevent my experiences leaking in to my interpretation of participants’ experiences?

In the end, I did two things. First, drawing upon my personal writing I wrote and analysed two scenarios which illustrated access barriers in health care settings. These are presented in chapter seven. Second, a fellow PhD student interviewed me twice, using my topic guides. I did this because I wanted to compare the amount, quality and detail of healthcare experiences that can be revealed in interview situation against that revealed through personal writing. Similarly I wanted to compare data generated from an interview with the actual experience it tried to reproduce. Beforehand I feared being frustrated at only being able to tell a fraction of my experience, which is perhaps indicative of the strength of the urge to tell the tale (Frank, 1995, 2002). But, perhaps due to the skills of the interviewer, this frustration didn’t materialise. Of course, much went unsaid, but that which was revealed represented my experiences and I found the process cathartic. Also, it did capture a similar level of detail as to my personal writings and that made me more optimistic about my research interviews. With the benefit of hindsight, I realise that much depends upon paying attention to the detail during the analysis. However, the interview did not provoke the same degree of self revelation as my writing: the

incident described in the second scenario presented in chapter seven was not mentioned in the interview, yet I believe it makes useful points.

The other reason for my being interviewed was to incorporate my experiences into my data analysis. Hence, my intention had been to analyse my interview transcripts along with the others and present it in the third person. However, upon reflection this felt disingenuous. I feared I would not treat it in the same way as other transcripts but would add material surreptitiously. I worried about the experience for readers upon finding out that a certain example or quote was actually from me. If I felt justified to use my experience, why not write in the first person?

### ***Pilot Interviews***

Between September 2003 and January 2004 I conducted five pilot interviews as a way of testing my topic guide and honing my interview skills. The five comprised four men and one woman who were recruited through friendship networks and an advert in the local paper. From these interviews four main points were learnt and led to amendments to my research design.

### **Reaffirming My Neutral Stance**

Despite intending to adopt a neutral stance as interviewer, in fact my style, comments and probes were those of an insider. This wasn't because I was trying to establish rapport as Oakley suggests (see above), rather I forgot my role and was responding as a friend. At times I had to make a conscious effort to stop myself sharing my experience. Further I took things for granted just as Du Bois predicted. For example, one participant highlighted a need for healthcare professionals to have a greater "disability awareness". Many understandings of what constitutes this awareness exist; hence probes should have been used to clarify the participant's intended meaning. Unfortunately I assumed I knew what he meant.

To learn from this, my interview preparation included reflecting and reaffirming my intended role. I also needed to take a naïve role, to probe and question participants' meaning of insider terms rather than taking them for granted. Similarly I needed to probe more so as to get the depth and detail of participants' experience, although

remembering that not everyone will want to divulge these (Kvale, 1996). To keep this in mind, the topic guide was reformatted to include examples of probes and follow-up questions so as to jolt my memory.

### **Impairment Matters in Data Collection**

One theme which emerged from the pilot interviews was that participants' experience of impairment influenced the pattern and content of health care encounters. For example, two participants made sense of their current health care encounters with reference to those experienced as a disabled child. To explore this further posed a problem: participants were not asked directly about the name and characteristics of their impairment and I would have felt uneasy asking such questions. This unease was derived from my personal involvement with the social model which renders medical detail of impairment irrelevant to the understanding of disability. Further, refusing to give medical labels is a form of resistance to the phenomenon of strangers who ask disabled people "what's wrong with you?" and expect to be told one's medical diagnosis.

Yet in place of asking for impairment details, I was making assumptions about them. This felt unsatisfactory and unethical so I considered devising a short questionnaire to collect some basic demographic and impairment data. However this seemed to be a ploy to get round my uneasiness. Upon reflection, what was needed to make the link between impairment and health care were descriptions of the influence of impairment / disability, and I needed to trust that participants would decide what I needed to know. The implications of this decision not to ask for impairment details will be considered more below.

### **Dropping Primary Health Care Focus**

My intention had been to focus upon participants' experiences of PHC. Yet while my questions all referred to PHC, participants spoke about their experiences with primary *and* secondary care, without making a distinction between the two. Moreover, what participants were telling me about secondary care was useful and participants clearly felt this was an important issue for my understanding of their

health care issues. So it made sense to drop the PHC focus. This risked the Project becoming unwieldy but it enabled participants to “set the agenda”.

The combined influence of my personal experiences and the pilot interviews resulted in two further changes to my research design.

### **Interviewing Participants Twice**

In terms of generating data, the pilot interviews provided breadth but lacked depth. Yet my personal experience suggested that the detail and depth were vital. In part, this reflected my novice skills as an interviewer, something I hoped would improve with experience. But the duration of the interview was also an impairment issue. Of the pilot interviews, the shortest was less than an hour and the longest well over three. The latter would have been impossible after my illness for reasons of fatigue and concentration. This may also have been an issue for some participants. Hence I decided to interview people twice, with each interview lasting no longer than an hour. There were further advantages to this. The second interview would enable me to follow up issues raised in the first and thus yield more detailed descriptions and explanations. For this reason, the gap between the two interviews was short, a fortnight to three weeks. Further, in two instances, the comparing a participant’s first and second transcripts was revealing analytically. One further change made to the research design and that was the employment of a research assistant, to enhance the accessibility of the interviewing process. A successful grant application to the University of Edinburgh Small Development Grants secured funding for this. This was a great success, enabling me to focus my attention and energy entirely on developing a relation with the participant and conducting the interview. This will be described below.

### **Interview Process**

#### ***Recruitment***

Using the strategy outlined above, recruitment of participants was slow and difficult. One reason for this could have been the Project’s title, *Disabled People’s Healthcare Encounters*. Perhaps this seemed irrelevant to disabled people who don’t have regular contact with the NHS. This was suggested by one participant whose friend

declined to be interviewed on the grounds she had little contact with the health service. Another problem could have been that people do not like talking about health and illness. All this was similar to Cornwell's (1984) experience: when participants realised they would be asked about their health they dropped out because they saw their health as good and didn't want to be seen as moaning about their illnesses. Thus they assumed that a health survey would actually be an illness survey.

In the end, personal contacts and snowballing proved to be the most effective recruitment strategies. Appendix one provides a breakdown of who was recruited through which channel.

### *Who Was Interviewed?*

In the event, 27 participants were recruited, including the five pilot participants. It is perhaps worth noting here that two participants had learning difficulties as well as physical impairments. Of these, one had a supporter at the interview and this was arranged by the participant. The supporter occasionally assisted the participant to work out what he wanted to say and then the participant told me. At the participant's request the questions for the second interview were sent in advance so he could discuss them with his supporter. An easy read, large print version of the interview summary was produced. The other participant with learning difficulties had no verbal communication. Her family carer was interviewed. I also spent time with the participant to get a sense of her. When analysing the carer's transcript I was mindful that there were two experiences being reconstructed: first the disabled person's as recounted by her family carer, and second the carer's experience of accessing and attending health care appointments with the participant.

Five participants told me they had mental health issues as well as physical impairments. They were interviewed in the same way as others. The fact that the interviews were only semi structured meant that I could encourage people to talk about mental health issues if and when they mentioned them.

The reasons why the sample size was 27 were two fold. The first was due to data saturation. Each participant's experiences were unique in terms of its content and the way in which it was reconstructed. I think this would have been the case however many participants were interviewed. Nonetheless, in the last four or five interviews, I was beginning to feel familiar with what I was hearing and understanding. At this point, pragmatism became an issue, and this was the second reason for the sample size. My recruitment networks yielded no further potential participants. Therefore if I wanted to increase further my sample size I would have had to do a further round of recruitment network. I felt I did not have time to do this.

### *Venue*

It was when arranging a mutually accessible and convenient interview venue that the barriers I faced as a disabled researcher had to be handled. My inclination was to make things as easy as possible for participants who were volunteering to help. But this was not always possible, given my needs. In part this was because many participants' houses were inaccessible to me, including those of wheelchair users. However, participants were very obliging and creative in their choice of an accessible venue so interviews took place in a shopping centre, hotel lounge, workplace, theatre and community cafés as well as the university. Only two problems occurred. One of these was a house with incredibly long, steep ramp tracks which I would not have attempted in any other circumstances than conducting an interview! Second, at one venue, a therapy centre, the physiotherapist asked me to interview the participant while he was cycling in the gym. The participant was happy, so I agreed. With hindsight, recognising my power, I should have explored other options so the participant had a real choice.

### *The Role of Research Assistant*

In all the interviews (except the pilots), I was accompanied by a research assistant whose role was to handle all the practicalities of the interview apart from conducting the interview. This had a significant influence upon who "I could be" in the interviews. Meeting with the participant and setting up the interview is a vital

opportunity for establishing rapport. In the pilots, this was a physical struggle because it involved handling papers, using recording equipment and making the space accessible, all things at the edge of my capabilities. Moreover, while doing this I felt very self conscious and this undermined my confidence. This is an example of what happens when the doing of routine tasks cannot be taken-for-granted. Precisely because one has to be aware of the minutiae of doing the task, one is distracted from the relationship with the other person.

By contrast, when the assistant handled these tasks, I concentrated on welcoming the participant, offering refreshments and working at making him feel at ease. I could treat the participant as I wanted to, unfettered by my physical limitations. In turn, I was much fresher and more relaxed when I began the interview. As argued above, the interview is a space where past events are reconstructed and that reconstruction is in part contingent upon the immediate circumstances. This suggests that there may be a relationship between my having an assistant and the quality of the data collected.

In addition to setting up the interview space, the research assistant took notes during the interview and transcribed the recording. This influenced my research design. Without the notes, I would not have been able to produce a summary before the second interview. Yet this was an important way of checking with the participant that I understood and interpreted his/her experience correctly. While it is recognised that transcribing is a way of becoming immersed in the data (Corden & Salisbury, 2005), I listened to the recording several times after each interview to ensure such immersion.

I amended the research information poster to reflect that I would be accompanied by the assistant. At the beginning of the interview I introduced the assistant to the participant and explained her role.

### *Interview Preliminaries*

At the beginning of the first interview, a brief overview of the Project was given and the format of the interview was explained. Participants were then given a copy of the consent form (see Appendix four) and we discussed each item.

### *Style of Interviews*

I aimed to make the interview informal. The topic guide (see Appendix six) for the first interview had four main questions, which were broad and open ended. They were designed to get people talking about different aspects of health care encounters: what services they used, their relationships with healthcare professionals, any access problems they experienced and whether they had ever had to get proof of disability from a healthcare professional. I then used probes and follow up questions to steer the participant to the issues which most interested me in and to get the detail about what happened, why and how they felt about it. I also made extensive use – perhaps overuse – of the summary technique, reflecting back to the participant my understanding of what had been said. This was a way of indicating I was listening and of checking my initial interpretation of what was said (Kvale, 1996).

Two participants were interviewed together at their suggestion. This proved very effective in terms of data generation as they bounced ideas off each other. The interview demonstrated the importance they attached to supporting each other. Rather than ask each of them questions I suggested they described their best and worst health care encounter and then asked further questions to draw out what I was most interested in. This worked well.

One participant phoned me the day before the second interview to cancel saying he did not want to go over it all again. I made no attempt to persuade him otherwise. On another occasion a second interview was cancelled by mutual agreement because the person felt there was nothing more to say. This person was the parent carer of a participant with learning difficulties who used non verbal communication. I felt it was inappropriate to probe the carer either about her own feelings or those of the participant.



In the second interview, again I used a topic guide (see Appendix six), covering expertise, managing impairment and how the NHS could be made more disability friendly. In addition, I drew up a list of questions for each participant, asking for clarification or for elaboration of a topic discussed in the first interview. These bespoke questions took priority over the standard ones as the aim of the second interview was to obtain more detail and depth.

### *Researcher – Participant Relationship*

A number of participants acknowledged my “insider” status. For example, two participants made comments about ‘not wanting to end up in a wheelchair’ but immediately looked up and said ‘no offence’. This was quite touching, as it indicated that they did not feel constrained by whom they perceived me to be, yet were nonetheless sensitive to that perception. Another participant drew an analogy between my reliance on a wheelchair and his dependence on a ‘note book system’ he had devised to compensate for his poor memory. The common feature of these remarks is that the wheelchair is instinctively interpreted as the paradigm case of disability and impairment and the participants position themselves in relation to it. While the first two participants were distancing themselves from wheelchair users, the third was trying to align himself with the paradigm case in order to make his hidden impairment apparent and significant.

Another participant referred to my insider status in a much more detailed way. For example, he talked about nurses being unfairly put upon, in part because of his high level of need. Thinking aloud, he reflected upon why he felt this as the nurses had never indicated that they were put upon did not even hint at it. Struggling to say this, he questioned me: ‘you must have felt like that?’. What is interesting here is that he takes for granted that our experiences would have been similar in order to explain something that he could not put in to words. So the participant may also make assumptions about shared knowledge when the interviewer is an insider. Later in the interview, I asked a question about the Wheelchair Service which was deliberately naive and from an outsider position. In response the participant’s stance changed

from being reasoned and keen to help to being mocking and forceful. In part I felt that this reflected his strength of feeling about the issue but it also felt as if he was irritated by my taking on an outsider status.

In a number of interviews I restrained my urge to engage in conversation. For example, one participant talked about the difficulty of getting impartial advice when purchasing a wheelchair privately. This is something I have experienced but felt it would have changed the dynamics of the interview to say so. In another example, a participant described several difficult and upsetting hospital experiences which were very similar to some of my own. Indeed as the participant spoke I felt quite emotional, although I remained in control. It would have disrupted the participant's opportunity to tell his tale if I had shared my story. Indeed, given that I was in a situation of power, it may have put him in an awkward situation about how to respond. It may have also constrained what he felt able to say for fear of upsetting me. However, in both cases I tried to express empathy for what participants were telling me but from a position of neutrality.

### *Impairment Matters in Interviews*

For reasons discussed above, I did not ask participants to name their impairment. However, all but three did so during the interview. In one of these three, I was unsettled by my urge to ask for the name of the participant's impairment. During his I couldn't get a feel for how his impairment was enacted, although it was clear that social responses to him were often disabling. My assistant shared my curiosity about his experience. Perhaps this curiosity was a sign of my intellectual laziness: rather than piecing together the experience he was describing, perhaps I wanted the quick fix of a medical label. Yet labels rarely reveal much more than a category. However these can be useful in placing people, understanding their situation in relation to others. Perhaps my unsettling curiosity was something similar to what participants were doing when placing themselves in relation to me as a wheelchair user (see above). The pertinent question here is whether there is broader social function at play here, something to do with needing to impose order or to have some sort of explanation for bodies which differ.

After the end of one interview, a participant asked about my impairment, assuming that it was the same as hers because I had recruited her through an impairment organisation. I explained I didn't have that condition but was reluctant to name mine. Yet Oakley's injunction is to reciprocate, and I felt this acutely as the participant had just revealed many aspects of herself. Before I could respond however, we were told to vacate the room (in the university). Hence the moment passed, something which I later regretted as it was an opportunity for me to experience reciprocating and moving beyond my comfort zone.

### *Post Interview Process*

After each first and second interview, I wrote impressions of each interview and the participant. These included my sense of the participant, the main themes of the interview, ideas for the second interview and reflections upon my performance as an interviewer. All these were coded and used both in the analysis and the writing of this methodology chapter.

My intention was to send participants a copy of the first interview transcript before the second interview. This is a recognised method for establishing credibility by enabling participants to agree or otherwise with the way in which the researcher has represented them (Seale, 1999). However, three of the first four participants expressed concern about the way they came across. For example, one commented that she went 'on and on', another was shocked to learn she 'didn't speak in sentences'. Also the transcripts were long and one participant apologised for not having the time to read it. I took all this to be a reminder that what makes theoretical or methodological sense in the academy does not always work out in the field. After the fourth interview, I decided to send participants a two page summary of the interview rather than the transcript. At the beginning of each second interview, the participant was invited to comment upon the summary. This gave useful feedback on whether my sense of the salient points tallied with what the participant felt was important and whether they felt my interpretations were accurate and fair.

Two participants made substantial comments about the interview summary. One challenged my terminology, saying he preferred "person with a disabilities" to

disabled person. We agreed that I would use his preferred term with reference to him but I would use “disabled person” for other participants. The second participant had shown the summary to his GP, who was unhappy with the participant’s description of his expertise. This was tricky. If the summary alone was amended the information would remain in the transcript and therefore be analysed. Yet, to amend the transcript raised awkward issues about the knowledge status of the transcript. To make the amendment would have been to recognise the fallibility of the interview process: at best, the transcript represented a reconstruction of reality which existed at one moment of time and from one point of view *but mediated* through the participant’s memory and any gloss he gave it. This underlines the fact that the knowledge produced in interviews is contingent and mediated. There was a further complication here. The participant was requesting that his view be substituted by that of the GP. This could be construed as medical paternalism, of the doctor knowing “the truth”. Yet the participant’s view was my interest, including that he valued the GP’s expertise even though the GP denied having such expertise. In the end, I did change the transcript. Otherwise inviting participants to comment upon the summary would have been rendered tokenistic as it did not lead to any change in the “real” data contained in the transcript.

In this section I have tried to contrast my intentions regarding the data generation process with what actually happened. In doing so I hoped to highlight how I felt participants’ perceptions of me as an insider, along with the disabling barriers I faced, influenced the interview process. The perhaps unanswerable question this raises, is whether all this has coloured the data collected. However, it certainly confirms that the production of knowledge is situated and contextual (Kvale, 1996).

### **Data Analysis**

My reading of the data has been an interpretive and reflexive one (Mason, 2002). That is I have tried to interpret “what is going on” in the reconstruction of the events, feelings and meanings described by the participants and then trace the connections between these and the ‘relations of ruling’ (Smith, 1998). In the process, I have also tried to take account of my influence on the generation and analysis of the data.

All transcripts, summaries and impressions were transferred into NVivo for coding. As with much analysis of qualitative data, the initial phase involved looking for general themes across all the data (Gibbs, 2002). Pieces of data which were similar were marked and linked. I regarded this as broad brush coding. These codes were mainly derived from my topic guides that in turn linked to my research questions (see Appendix two). These codes were:

- Experiencing impairment
- Managing impairment
- Disability Access and health care
- Managing use of the NHS
- Relationships with healthcare professionals
- Medicalisation

There were two main difficulties with the broad brush coding. First, I was not clear about the boundaries and interrelationships between the themes. For example, many instances of managing impairment were also instances of managing use of the NHS. Although the same bit of data could be coded both ways, the underlying issue was a conceptual one: my “working definition” of each theme was vague. This is not necessarily a problem insofar as the codes need to be flexible at this stage in order to incorporate unanticipated data which is related to the theme in an unusual way or challenges its definitions or boundaries.

The second problem was a lack of clarity about the angle of interest in a phenomenon. For example, the code *managing use of the NHS* seemed to become a residual category which comprised descriptions of any health care encounters not coded elsewhere. Was my interest here concerned with the appropriateness of the services being used, the outcome, the way it was handled etc? On further reflection it became apparent that “my angle” needed to be determined by three related questions:

- What does the encounter tell us about how disabled people use the NHS?
- Is there a clear boundary between encounters for impairment related and non impairment related issues?

- Do impairment or disability issues influence the actual encounter?

Having completed the broad-brush coding, I started reading through the text at each code in order to discern themes emerging within it. In other words, an inductive approach (Baikie, 2003) was adopted, whereby the direction of analysis was from the experiences reconstructed by participants to the generation of new concepts and frameworks in which they could be understood. Some useful and fresh concepts arose from this process. For example, a number of participants described the support they derived from meeting others with the same impairment. What was especially interesting was that an aspect of this support was “being with” similar others. I called this “impairment solidarity”. However, again there were difficulties. It felt as if I was abstracting from participants’ lived experience rather than understanding it and placing it in the relations of ruling (Smith, 1988). I was neither getting the detailed picture nor the bigger one but was stuck in the middle of the two. To make matters worse, I became sidetracked by trying to create an abstract logical framework of codes to represent the text. Having done that, I then tried to summarise each occurrence coded to each part of the framework. Although this structured the data, it did not give me space to really engage with what was being said. This was frustrating and stultifying.

At this point, a colleague advised “ask the data questions”. Needing a fresh approach, I began to generate analytical questions by going back to my research questions, tracing their connection with the interview and broad brush questions and then refining them in light of what was already known about the data. The questions (see Appendix two) that proved most fruitful were:

- How do disabled people talk about their bodies?
- Are emotions implicated in the embodiment of impairment? How?
- Are disabled people “experts” when it comes to handling relationships with health care professionals? What forms does this “expertise” take?
- What factors influence the development of expertise?
- Does patient expertise conflict with health care professionals’ expertise? What happens? How does it affect relationships?

- What range and type of access problems do disabled people face in health care contexts?
- What factors shape access issues in the health care context? Are some access issues unique to the health care context?
- Who takes responsibility for dealing with access issues in health care contexts? How? What does it involve?

I started to deconstruct each portion of data that related to a question (Wainright, 1997), breaking it down and asking “how does it this piece of data relate to social structures and relations?”. Thus, I established a dialogue with the data, writing my answers by each bit of text. Having done this for each question I realised I had three main themes and each could be explored in a chapter. These were:

- Experiencing impairment
- Expertise and the disabled person/healthcare professional relationship
- Handling access issues

It was at this point that I started writing and reading (again). I will describe that final analysis phase at the beginning of the next three chapters.

### *Presentation of the Data*

All participants have been given pseudonyms to preserve anonymity. As the disability community is quite small, there is a risk that some participants may be recognised from their biographical details, so some of these details have been changed. The same risk applies to accounts of some health care encounters, particularly where these relate to the nature of impairment. These are more difficult to disguise because in some places they form the substance of analysis. However, I have tried to ensure anonymity by making changes wherever possible. Where it is relevant to the discussion, I have described the characteristics of a participant’s impairment - for example a late onset neurological condition, but not the name of it. The exception to this is where the participant has named it in an unusual way, in which case a direct quote is used. There are different views concerning how to edit participants’ quotations, which are presented in the analysis of data (Corden &

Sainsbury, 2006). On the one hand, if quotations are regarded as evidence or as a means of representing the voices of participants, then editing should be minimal and should reflect its original spoken form, for example by retaining the “ums” and “ahs”. On the other hand, limited but judicious editing may improve readability. Further, some argue that it is ‘patronising to reproduce the hesitancies and false starts in normal speech’ (Corden & Sainsbury, 2006:18). This tallies with how some participants felt on reviewing their transcript (see above). I am persuaded by the latter arguments. Accordingly, I have removed “ums” or “ahs” and on occasion made cuts to the quotation for the sake of clarity and brevity. These cuts are indicated by three dots. I have used square brackets in quotations to clarify meaning or to replace words which could jeopardise participant anonymity, for example the name of a family member or of a health institution.

## ***Discussion***

This chapter has given an account of the design and execution of my research. By way of conclusion I want to consider the validity of the research or, to put it another way, on what basis can I ask you to trust the accuracy and integrity of the analysis that you are about to read? Trust is needed on two grounds. The first of these is that the data on which the analysis is based is a faithful retelling of what participants told me and that, in turn, the data bears sufficient relationship with the participants’ notions of reality. Second trust is needed that my interpretations are reasoned and plausible in the given context in which they were made. What should count as a fruitful measure or test of validity when using qualitative research methods is a matter of considerable debate (see, for example, Mason, 2002, Maxwell, 2002, Seale, 1999). However, there are several measures which can be applied to my work. While none give decisive or compelling proof of trustworthiness they do give some indications of it. One of the elements which contributes to Lincoln & Guba’s notion of credibility (as discussed in Seale, 1999) are “member checks” or participants’ feedback on the researchers’ accuracy and interpretation in representing their accounts. This was done through inviting participants to comment upon the written summaries of the interviews. A further element of credibility is the provision of a reflexive and critical account of the research process. This has been the purpose of



this chapter and is continued in the following three chapters, where I discuss the selection and interpretation of the data presented. Further, my style of data presentation illustrates how interpretation was reached. This also satisfies Mason's (2002) stipulation that the researcher should make transparent the basis on which he makes claims or arguments based on the data so that readers can judge validity for themselves. Finally, I cannot make any claims to external validity, no generalisations can be made about the applicability of my analysis to other situations. This is because the data and its analysis are infused by my biography and embodied experience of disability and impairment.

## CHAPTER 6

### Body Talk

In this chapter I want to use my interview data to explore how impairment is embodied and embedded in the mundane details of everyday life. The analysis which will be presented here is the result of an iterative process which on the one hand, involved analysing, questioning and writing about the data, and on the other involved developing my own thinking through reading contemporary sociological texts about embodiment and lived experience. As a way of setting the scene for this chapter I will begin by discussing this process before going on to present the analysis.

#### *Questioning the Data*

One of my initial research interests was managing impairment, what disabled people have to do with or for their bodies in order to live well from day to day and how this is influenced by health care encounters. Hence one of my “broad brush” codes (see chapter five) was managing impairment. Initial analysis suggested that this comprised three elements:

- **Lived Experience** of disabled people: how particular embodiments require people to act and be with their bodies in certain ways. For instance, someone with balance problems has to be constantly mindful of her body when transferring: that is the technique by which a wheelchair user moves from one surface to another, for example from wheelchair to the toilet.
- **Regular Management Tasks** which people have to do in order to maintain functional levels and/or keep well, and the role the NHS does and should play in supporting this.
- **Different Styles of Management** that disabled people adopt and why.

The first two of these are clearly related, but whereas the former primarily involves the relationship between body and Self in the context of everyday life, the latter involves relationships with healthcare professionals in the context of specific, time

limited encounters. Therefore it made sense to split the presentation of the data and make lived experience the focus of this chapter and focus upon relationships with healthcare professionals in chapter eight. The style of management, the choices and constraints faced by disabled people in dealing with the impaired body is integral to both chapters.

My next challenge was to analyse further the lived experience data in a way which incorporated both the influence of social structure and the agency of disabled people. Reading through it, what participants seemed to be telling me was that *lived experience incorporated a doing with and for impaired bodies in a disabling world*. This is illustrated in the following passage from my second interview with Thomas:

*'It has always been a struggle to do anything; I have usually been able to put my socks on okay because I have always been able to work out how to do it. I have been able to work out where I should sit in order for my body to be at the right angle to do it. It has sometimes been a problem when I have gone away somewhere, like a hotel for a day or two, and I have found that they have furniture, particularly beds that are different height and I can't reach down far enough. That has happened in the past' (2nd interview)*

How did we get from questions about health care to the putting on of socks? What did it tell us about Thomas' relationship with his body that he could recount these details to me, a stranger? Is sock putting-on usually a taken-for-granted activity which most people would struggle to explain about how they did it? Is it only when Thomas is putting his socks on in an unfamiliar place that the task is no longer taken-for-granted?

These questions only occurred following another round of coding which involved "asking the data questions". These questions were formulated by re-visiting my research questions to remind myself how they related to my interview topic guide. I then refined these in the light of what I knew about the data. My first set of questions was too detailed: in effect interpretation of the data was required in order to code it. This made it difficult to ensure consistency across all the transcripts and it felt as if I wasn't listening to what participants told me. I realised what I needed to know was how, when and why participants talked about the body. I did this by reading through the transcripts again and coding to these much simpler questions:

- In what circumstances did disabled people talk about the body?
- How did people talk about the body? Why? Who didn't?
- What forms of relationship or modes of awareness did people have towards their bodies?
- What tasks comprise the daily doing and management of impairment?

The data coded to these questions form the basis of this chapter. Recognising that writing is an important part of the analytic process, and having completed a draft chapter, I then re-read all the interview documents, to look for evidence which shed new light upon or questioned the interpretation of the data presented.

### ***Analytic Frameworks***

My next challenge was to find an appropriate framework or context to facilitate further interpretation of the data. The substantive part of the body talk data comprised descriptions of what people did to, or felt, about the impaired body in the course of everyday life. I started thinking about this using Tighe's concept of disability as work, reviewed in chapter two, which highlighted the disability related tasks which the disabled women in the study had to do every day and the additional tasks they did in response to pressure they felt to conform to non-disabled standards of health. As useful as this was in capturing this extra dimension of lived experience that disabled people may face, it seemed to lack any sense of impairment related work. Yet this seemed to feature in my participants' body talk, along with a sense of how they lived with and through an impaired body in a disabling world. In other words, it lacked any sense of embodiment, of the 'perceptual experience and mode of presence and engagement in the world' (Csordas, 1993:135).

At this point I came across Mol & Law's (2004) study of living with diabetes. They argue that as well as having and being a body, we also do the body through daily practices. An essential ingredient of this doing is self awareness: it is self knowledge of the body-I- am that enables us to act upon the body-I- have. From this starting point, Mol & Law examine the daily practices that people with diabetes do to avoid hypoglycaemia. This doing has many levels, for example people have to learn from healthcare professionals about diabetes and the tasks and skills that the body-I-am

has to do to the body-I-have in order to manage it. People then have to do the measuring of blood sugar levels which involves the ‘doing hand’ pricking a finger on the ‘being done to’ hand, placing the strip into the monitoring machine, reading the level and deciding what further action they need to take. This and other doings become incorporated and infused into lived experience, so for one of Mol & Law’s participants, avoiding a “hypo” meant sitting on the kitchen floor at night eating yoghurt with sugar in it, having forgotten to eat before going to bed. Bodily “doing” is also constrained by social roles and relations; for another participant, a road digger, finding a hygienic place necessary to monitor blood sugar levels was extremely difficult.

One of the strengths of Mol & Law’s concept of doing the body is that it facilitates a multi-level and embodied analysis. They specify the detail of doing, paying attention to the phenomenological experience of the body acting upon itself, they show that having a disease requires agency to do the necessary physical and cognitive tasks to the body. The doing of these tasks is shaped and shaped by lived experience and the broader social context. Thus we come to see how diabetes is enacted: we come to understand diabetes as the activities people do in response to their bodily condition in the context of their everyday lives, constrained by social roles and relations.

There is some similarity between Mol & Law’s concept of doing the body and Crossley’s (2006) concept of reflexive body techniques (RBTs). They both require reflexivity, the body-I- am becoming aware of the body-I-have in order that the former can act upon the latter. However, Crossley’s concern is with the daily tasks everyone does to maintain or modify the body, not just those associated with a particular condition. Hence RBTs range from washing one’s hair to having a tattoo and all have as their purpose ‘to work back upon the body so as to modify, maintain or thematize it in someway’ (104). RBTs are relevant here to highlight the ordinariness the body reflexively doing upon itself. While doing impairment may comprise some tasks that non-disabled people don’t have to undertake, the act of reflexive doing in everyday life does not of itself mark out disabled people from their non-disabled counterparts. This suggests that if an analysis of doing impairment proves useful then consideration should be given to mapping a range of impairment

related RBTs in a similar fashion to that which Crossley has done for non impairment related ones.

The concepts of RBTs, and especially doing the body, provided the framework in which the body talk data was analysed as it seemed to negotiate through tensions found in the literature. It enabled me to acknowledge that impairment can be an important explanatory factor (Shakespeare, 2006) in some aspects of disabled people's lives, yet never in a way which assumes that impairment is pre-social because what is done to the body is always mediated through the social and cultural (Crossley, 2006). It also enabled me to explore similar ground to that covered by the medical sociology literature on coping and adjusting to chronic illness/impairment but in a way which is embodied and enmeshed in social relations. So for example, Kelly & Field (1996) argue that 'the physical problems which chronic illness generates' are the epicentre of the 'coping experience' while attending to social relations and the reconstruction of self is secondary (247). By contrast, my contention is that 'coping' is actually management and that management is mediated through social relations and social roles. Coping is pejorative and suggests something that one puts up with, whereas management implies agency and purposive action.

However, not all the body talk data comprised examples of doing impairment. A small proportion described the circumstances in which participants became aware of the body for an impairment related reason. This awareness differed from doing in that it didn't require the participants to immediately act upon the body. Rather it caused them to reflect or contemplate certain features of it or, indeed, on some aspect of doing impairment. In presenting this data my aim is somewhat perverse. By looking at the circumstances in which disabled people become aware of the body I hope to demonstrate the impaired body, as with the non impaired body, is often taken-for-granted. I will also highlight the different levels of taken-for-grantedness: for example, at some points it is the body itself which is taken-for-granted and at others it is bodily activities. This provides a useful backdrop for the doing impairment analysis for two reasons. First it is a corrective to any impression that the extent and scope of doing impairment suggests that disabled people are always

aware of their bodies. As we saw in chapter two, this impression is sometimes given in the phenomenological and medical sociological literature but challenged by Disability Studies literature (see, for example, Hughes & Paterson, 1997, N. Watson, 2000). Second, in many instances doing impairment emerges as a result of this awareness.

I will now present the data on the impaired body and taken-for-grantedness, followed by the data on doing impairment. The final section will discuss the implications of the analysis.

### ***The Impaired Body and Taken-for-Grantedness***

During the interviews, one of the occasions which prompted participants to talk about their bodies was when they described the onset or progression of their impairment. This is perhaps not surprising given the arguments that we become aware of our bodies when they change in some way (Cunningham Burley & Backett Milburn, 1998), and that illness disrupts the lived body (Toombs, 1988). One notable feature of this form of body talk was how deeply the functioning of the body is embedded in the minutiae of everyday life. This is best illustrated by the experience of Carol, a former nurse who has a progressive neurological impairment:

*'I would be tripping and falling while walking my dogs for no apparent reason... I couldn't clap you know if you went to the theatre ..because the pain in my hands was so sore...so I just said to my friend "well I am not applauding because I can't do it"...' (1st interview)*

Here we see how routine bodily activities such as walking and clapping which are usually done in a taken-for-granted manner become problematic in a particular time and space: tripping while walking the dogs forces Carol to become aware of her body, albeit momentarily. In a reflexive mode, Carol realises that the sensation and the act of tripping suggests something is wrong. The effects of impairment, the bodily doing of impairment if you like, emerge from fractures in the relations between the body and the world of objects. It is during these fractures that the body ceases to be taken-for-granted. This suggests that the biological aspects of impairment cannot always be separated from the social context in which they are experienced and so challenges one of the main principles of the social model of

disability. A further point is Carol's need to account for her body's behaviour, for not clapping. The physical movements involved in clapping have no intrinsic value and meet no functional need but comprise a symbolic cultural act. To avoid Carol's not clapping being misinterpreted as a cultural transgression, she brings her friend's attention to her strangely functioning body. In doing so Carol avoids another moment of pain filled awareness that she experiences when clapping.

Peter, a former oil rig worker with a degenerative neurological condition, described becoming aware of the usually taken-for-granted act of walking through observing the walking of another.

*'... I got off the bus, took off from the bus stop at the same time as a mother pushing a buggy. She just totally sauntered past me. I thought I am going as fast as I can, pushing nothing, and she wasn't even breaking a sweat. And yet she is away.'* (2nd interview)

What is not clear here is the content of Peter's awareness: was it his body as an object, the bodily sensation of 'going as fast as I can' or a comparison between this and 'going as fast as I used to'? At this stage, Peter did not know that through walking he was doing impairment, enacting it step by step. Later, he gets a sense of this, feels it, irrespective of whether he had a diagnosis:

*'...walking along a bend, you have to make sure you know where you want to walk, where you want to place your feet.'* (1st interview)

Here Peter displays an unusual awareness of a taken-for-granted activity, walking. However, this does not necessarily imply that for Peter (impaired) walking is no longer taken-for-granted, just that in reflexive mode he knows that his walking has changed and consequently sometimes he has to be aware of where he places his feet.

To go back to the sauntering mother, Peter's interpretation of being overtaken was culturally mediated. He assumed that as a man he should be able to walk faster than a woman, especially one pushing a buggy. When it becomes apparent that he can't, Peter reflects upon his body's properties and performance. As this was the culmination of a series of moments of awareness of strange happenings and bodily sensations he decided to seek medical advice.



As we saw in chapter four, Shildrick & Price (1996) argue that one of the many ways in which disability and impairment is constructed is through the claim form of the welfare benefit Disability Living Allowance (DLA). This is demonstrated by Elspeth's account of completing her DLA form with the help of her Occupational Therapist (OT). It also provides insights into circumstances where the doing of routine daily activities becomes modified by impairment, and how this happens without the person being aware of either the modification or the bodily change which precipitated it. Elspeth described herself as 'one of the walking wounded with MS'.

***Elspeth:** '...my OT asked the relevant questions...because if someone had said are you still managing to cook a meal...I would say, "of course I am"...and then [she] said..."do you peel the potatoes" and I said, "well no, I can't hold the potato peeler anymore"... "what happens when the pan is heavy?"... "well I get [my partner] to lift it"... you don't actually realise what you've done is necessary...It's not a choice...'*

***RB:** 'So you actually make these adaptations without being aware?'*

***Elspeth:** 'Yes...there's a bigger adaptation that you have to make that's noticeable you know...like when we got the set of wheels [i.e. wheelchair], that's noticeable...but when you stop buying big potatoes for baking and we buy the wee ones with the skins on so you don't have to do anything with them ...that's a detail...' (2<sup>nd</sup> interview).*

Elspeth (and her partner) had changed their cooking routine so easily and with so little awareness that Elspeth's taken-for-granted body had seamlessly incorporated changes in her arm and hand function. It was only when the OT asked very specific questions that Elspeth became aware of changes in her upper body function and how that influenced what happened in the kitchen. The fact that the OT knew what questions to ask so that Elspeth's bodily experience could be made visible and shaped to meet the eligibility criteria of DLA, is a good example of Shildrick & Price's argument, that impairment is constructed. It is also an example of how external bureaucratic factors can return awareness to the body.

To go back to why Elspeth was able to incorporate bodily changes in her taken-for-granted body, this seemed to be contingent upon two factors: Elspeth being able to

change the kitchen environment and the type and degree of bodily change. Looking at the former, it is as if Elspeth implemented the social model in her a domestic situation: for example, getting her partner to lift heavy pans removes one of the barriers which Elspeth faces when cooking. This process of barrier removal was influenced by Elspeth's social circumstances: having a partner who was able to help and being able to afford to change her diet and kitchen equipment to suit her impairment related needs. Gender issues may also have been at work. Elspeth appears to want to take an active role in the kitchen. Equally, Elspeth's partner is willing to buck traditional male roles by assisting in the kitchen.

The second factor which enabled Elspeth to take her changing body for granted was the form that these changes took. Elspeth describes how some changes require adaptations that are 'just detail' and others changes that are very noticeable. So the need to purchase a wheelchair cannot be taken-for-granted in the way that buying small potatoes can. Different types of impaired function have very different social and cultural connotations as well as different practical consequences. This is a point not recognised by the social model of disability. Yet the detail cannot always be taken-for-granted either: at certain moments the type of potatoes on the shopping list becomes no longer a choice, but a necessity and one which emerges from awareness of the condition of the impaired body.

The final point I want to make here concerns Elspeth's feelings about being made aware of bodily changes through bureaucratic means:

*'Oh it's horrible...It's absolutely horrible...I hated it...I really really hated it [filling in the forms] ...but it's good in a way that it forces you to look at your true position as well...and there are an awful lot of people who are in denial and you know' (2nd interview)*

Being able to incorporate bodily changes in the taken-for-granted body hides the 'true position'. But which sense of the body is the 'true position'? As we have seen it's not the taken-for-granted body, but invariably neither is it the reflexive body. Given that there is a to-ing and fro-ing between the taken-for-granted and reflexive body, Elspeth would have had many reflective moments prior to completing the DLA form. It is only through a very particular form of interaction with a healthcare

professional that reveals the extent of functional impairment, and that revelation is mediated by Elspeth's reflection upon the body in a very particular context, not upon the body *per se*. But then there is a further complication: the process of revelation provokes the emotions, emotions which I take to be embedded in Elspeth's hating the process. These emotions influence how the body is experienced, so are these emotions part of the 'true position'? If so, will the 'true position' change as these emotions become muted over time even if impairment stays the same? What I would suggest is there are many 'true positions' and each one comprises different elements of embodiment experienced in a number of different environments and sets of social relations.

I now want to move on to my final example of how awareness can be shifted to the impaired body as a result of having a condition which is fluctuating. Carl, a welfare advisor who retired on health grounds, described how he became aware of his body by comparing elements of his lived experience from one day to the next:

*'I have good days and bad days. Today is a relatively good day and so I was able to walk to the door and get the door for you. That was quite good. But there are other days when I really struggle to get from here to the lift. It's a long plod. But today it's not too bad. Sunday it was rubbish. But that's just the way it is.'* (1<sup>st</sup> interview)

The pertinent question here is do significant daily changes to the performance of body ever become taken-for-granted? Unfortunately, I didn't think to discuss this with Carl hence it is difficult to discern from the rest of the interview. However, Carl did say he would find be useful if

*'there was some sort of check up. They can say, well, "last year your mobility 90% and now this year its 60% or whatever" ...a bit more sort of scientific rather than me just going well before I could walk that far and now I can only walk that far'.* (1<sup>st</sup> interview)

This suggests that Carl wants to counter or legitimate his reflexive awareness of his ever changing walking performance by having it objectively measured and monitored by others. This may reflect dominant biomedical discourses that imply the body can be measured and therefore controlled. But it also suggests that repeated moments of awareness of bodily changes have an impact *in addition* to their

immediate impact on physical function. This is supported by the following comment from Ed when recalling his (slightly tongue-in-cheek) reply to someone who had said he looked well:

*'my life is never boring. I said "imagine the excitement of lying in bed in the morning when you have just woken up and speculating on what part of your body is not going to work today. It may have worked yesterday and it may work tomorrow but it may not work today". I said " but then once I have gathered up enough courage to get out of bed and set foot on the floor at least I know what the whole objective of that day is". She said, "Oh what's that [Ed] ". I said, "to avoid falling over." '(2<sup>nd</sup> interview)*

This suggests Ed has incorporated a reflexive sense of his ever changing body into his daily routine. Each morning Ed goes through the ritual of getting a sense or gaining self knowledge about how his body will work today. In other words what Ed takes for granted is that he *can no longer take-for-granted his bodily performance*. This is something many people experience especially as they age (Cunningham Burley & Beckett Milburn, 1998). But there is another level of taken-for-grantedness here. The person Ed is addressing who said he looked well has taken-for-granted that how someone looks is an indication of how one senses the body. Either that or she had not expected Ed to give an authentic, bodily grounded response.

In this section I have discussed some of the circumstances in which disabled people become aware of their impaired bodies. These included the nature of the physical environment, casual remarks and bureaucratic procedures. The degree of significance that the individual gives to that awareness will vary depending upon both individual and social factors. Carol and Peter each described one of many moments which indicated that something was wrong and they needed medical advice. The moment of awareness Ed described enabled him to voice his bewilderment, and perhaps frustration, with his ever changing body. Of course, when participants described moments when they became aware of their bodies, they were also implying the opposite, that they experienced many moments when they were not aware of their bodies, when they took the body for granted. In this they are no different from non-disabled people. Nonetheless, as we shall now see, impairment and disability influence lived experience.

### ***Doing Impairment***

This chapter will now proceed by presenting the analysis of body talk in the form of a number of examples of doing impairment. In selecting these examples I aimed to include a range of instances of doing impairment by participants with different types of impairments and life circumstances. To ensure a multi level analysis (Mason, 2002) as implied by Mol & Law's approach for each example of doing impairment presented I aim to consider:

- Why it can be interpreted as an example of doing impairment
- How doing impairment is integrated (or not) in lived experience
- The agency involved in doing impairment
- How it is connected to and shaped by social structures

The first of these is necessary to pin down and explore what I mean by “doing impairment” and whether it is a useful way of understanding disabled people's experiences. By making this exploration explicit readers should be able to judge this for themselves. These levels are best conceived as dimensions, with the need to “do” impairment in a particular way emerging from and influencing one or more of the dimensions. Nonetheless, each example will start with the individual's description of doing because that is where doing is initiated and experienced.

### ***The Body Doing to the Impaired Body***

Many disabled people have to incorporate medical tasks into their daily routines (Strauss *et al*, 1982). This was the case for Betty, who had an autoimmune condition and had to use an oxygen/air machine at night. The process and experience of using this machine involved a number of different tasks. It is these tasks which I am now going to analyse as three layers of doing impairment.

The first of these layers was the learning the “technical doing” of setting up and operating the machine. Betty’s account of this suggested it was inexpertly handled by hospital staff: the machine – an ‘old metal contraption’ - was ‘dumped’ on Betty’s bed without explanation, nursing staff on the ward didn’t know how it worked, she wasn’t told about cleaning the filters which increased the risk of bronchitis, and the doctor ‘literally jumped down’ Betty’s throat, blurting out ‘“you can go to sleep and not wake up!”’ (1st interview). It sounded as if the biomedical context only objectified Betty’s body. Also its day to day practice disrespected Betty’s body and her sensibilities towards it. Further, while the prescribing and designing of medical equipment requires medical knowledge, in a hospital setting the practice of using it is often dependent upon local conditions of who did what in each instance of its use.

One can speculate that this inexpert teaching contributed to Betty’s anxiety about using the machine when she first went home from hospital:

*‘I tell you it was midnight, after midnight, before I went back through to my bedroom because I was frightened that I wasn’t going to set it up properly and it was not going to work. You know I was just so frightened.’ (1st interview)*

This brings us to the second layer of doing, which involved Betty acting upon her body in what Crossley would call a RBT. When setting up the machine, Betty had to touch her face, tolerate the sensation of the mask round her head and get use to the noise the machine made. She also had to do this whilst experiencing the fear of not being able to set up the machine and feeling the responsibility of having to do a nightly life or death task alone.

While this ritual of nightly doing continues, Betty’s attitude towards it has changed. She has a new machine

*‘... that is easier to cope with and I know about it now, you know four years down the line I’ve got to grips with it.’ (1st interview)*

Getting to ‘grips with it’ suggests that using the machine has become part of her lived experience: it has been incorporated into her nightly routine of RBTs, a routine that most of us do but in individual ways. Thus doing impairment can become part of the ordinariness of everyday life. Betty is still doing, but perhaps having got used

to the bodily sensations experienced when using the machine and setting it up, the situation is now less emotionally charged. Betty has also developed expertise in using the air machine, perhaps becoming more technically accomplished than the nurses at the hospital.

The third layer of Betty's doing of the air machine concerns the administrative tasks, the bureaucratic doing, that is required. The machine is inspected every quarter, so Betty has to be around for that, she has to arrange for a machine to be delivered to her mother's house or holiday venue when necessary, and she has to deal with the NHS cheque which is a contribution to the higher electricity bills which are the result of using the machine all night. Betty observed

*'...you need to find out yourself what to do. I've had to phone up and ask what you do, so there is a procedure it's a few phone calls to get everything in place' (1st interview)*

While this bureaucratic doing may not be particularly burdensome and may become integrated within lived experience, it nonetheless has to be done. It is part of the experience of impairment for Betty.

What do we gain by using the concept of doing impairment in order to understand Betty's experience of using the oxygen air machine? On the one hand it enables us to break down and specify one of the tasks that has to be done in order to live – in Betty's case quite literally – with an impairment that is embodied in a very particular way. On the other hand it enables us to show how impairment doings are an integral part of lived experience. The concept helps to hold the tension between these two, between impairment being just a part of lived experience, yet also requiring the doing of additional tasks. We can also lay down a marker here of one of the ambiguities of the concept: does doing impairment refer (just) to the bodily task and associated bureaucratic tasks needed to use the machine successfully? Or does it also, or just, refer to the process of doing, the way in which it is enacted? Or both? In this example the focus is on the former but this is something I will monitor as we look at further examples.

## ***Doing Energy for the Impaired Body***

The next example of doing impairment I want to explore concerns the tasks associated with energy /pain management – an issue discussed by six participants. These tasks constitute one of the most obvious forms of doing and have the most distinct boundaries. Energy /pain management is also an aspect of impairment management which has been discussed in the Disability Studies literature, usually to make the argument that the social model of disability has limited scope for analysing the array of barriers and impairment related difficulties experienced by people with ME (Myalgic Encephalomyelitis) (see, for example, De Wolfe, 2002, Wendell 1997, 2001). As we shall see, my findings suggest that energy management is an issue for people with several different types of impairment. Further, the concept of doing impairment can analyse both the impairment and disability elements of energy management in a unified way.

The first layer of doing energy management involves a cognitive doing based upon ‘knowing your body inside out’ as one participant put it. One has to be able to sense how much energy one has, how much is needed for a given activity in a particular circumstance and what quality of energy needed: for example reading a book requires a different quality of energy than a walk around the garden. Energy management also requires a certain bodily attitude towards itself, one that it is willing and able to prioritise the body’s energy needs. Again, energy management can be seen as a form of RBT insofar as most people “do” energy management, particularly given the fast pace of contemporary life (Wendell, 1997), but perhaps in a more intuitive, less calculated way. However, for some disabled people, as for those in middle years (Cunningham Burley & Backett Milburn, 1998), the process has to be deliberate, requiring self discipline and skill to “pace” activities, interspersing them with adequate time for resting. Furthermore, for these people the consequences of *not* doing energy management can put health and bodily well-being in jeopardy.

For George, who has a rare bone condition, energy management meant taking



*‘...concentration off other things...it can be quite tiring...you have to sort of allocate time to do not very much...just relax...’ (1<sup>st</sup> interview)*

It may seem perverse to argue that allocating ‘time to do not very much’ is a “doing”. Yet for George the well- being of his impaired body required him to structure his lived experience around this. The “doing” then is the need to repeatedly make a decision in favour of resting rather than doing other activities which maybe more enjoyable or satisfying. Here, by considering the consequences of doing – less time for other activities - we trace the ripples of impairment effects in lived experience. But does this lead to a greater understanding of the experience of disabled people or does it risk overstating the effects? A further point to note is that doing energy management influences embodiment. Bodily sensations, such as tiredness or feeling rested, in turn influence one’s emotional and cognitive attitudes, both in general and in particular, towards having to make decisions in which energy management has to be a key consideration.

For other participants, making decisions about energy management was much more of an ongoing struggle than it appeared to be for George. Interestingly, this struggle was often expressed in a way which evoked a dualism between the mind and the body. For example, Halley commented:

*‘...to start with it would be 70% me [i.e. the mind] that won the argument. Now I would say that I would be lucky if I get 40% me. ’ (1<sup>st</sup> interview)*

What’s apparent here is that “doing” energy management offers no guarantees of success. In the past, with careful management, Halley could do the activities she wanted 70% of the time but now it’s down to 40%. It is Halley’s progressive neurological condition that places constraints on the success of her doing energy management. Una also talked about the doing of the struggle to ‘pace’ her activities but, in terms of what happens if she doesn’t pace, she doesn’t “do”:

*‘I get lazy and I can’t be bothered to pace and then I pay the price...but that’s just living, that’s just being a human being and thinking “oh sod it I can’t be bothered to be good all the time”, it’s boring its really boring!’ (1<sup>st</sup> interview)*

This demonstrates a further value of the concept of doing in that it allows for the fact that people do have choices, that they exercise agency about whether and how they

do energy management, albeit that those choices are constrained in ways which will become clearer below. The importance of agency was made very explicit by Diane, who has an autoimmune disease which makes her joints stiff and painful:

*'When I was first diagnosed I would always think "Oh I cannae do that because that would really hurt...or I would be so tired or that's too much effort" ...Now I will just go do it and then I will worry about the pain later, you know but at least I've had a good day.' (1st interview)*

It took Diane ten years to shift her approach because

*'it took that long to work out that there wasn't going to be a cure and that it [i.e. her condition] wasn't going to go away. I thought "if I'm stuck with this let's make the best of it"' (1<sup>st</sup> interview)*

So Diane does energy management by (sometimes) choosing additional pain and tiredness as a sacrifice for "having a good day". This suggests Diane has a degree of confidence in her ability to live through or do the pain and tiredness made worse by having a good day.

A second layer of doing energy management is the "doing" of the social relationships and consequences which emerge as a result of the interaction between social structures and disabled people who have limited energy. Una often has to do a certain form of social relationship because her impairment is hidden, and it is hidden *precisely because* she "does" energy management successfully. Sometimes Una is superficially judged as 'being well' by others, including representatives of social institutions such as the Benefit Agency and members of the public. This leads them to question the legitimacy of her disability status and her claims for appropriate support services, especially Incapacity Benefit. Una described how she responds to this:

*'I've said to people come and live with me for a week and see what my week is like, see what I am like after a day's work and why I have to be flat on my back for a day after. You report this stuff and you can see them looking at you thinking "sure you are fine". But why on earth would you make it up? Why on earth would you go through that process if you didn't have to? I just see it as trying to educate people now'. (1st interview)*

Una “does” the task of educating others by describing how her doing of energy management structures her lived experience. This suggests that people’s lack of insight into the day to day reality of disabled people, into their day to day “doings”, is a source of prejudice and suspicion about disabled people. Yet there is a balance that needs to be struck: what’s important is that doing is acknowledged *and* seen as one of many elements of doing the mundane in daily life. This is a point which I will return to in the discussion below.

Meanwhile for George, one of the consequences of having to do energy management and healing from fractures was that he had to take ‘time out’ from both university and employment. What could be an issue here is the temporal structures of these social institutions and their inability to be sufficiently flexible to take account of those who “do” energy management. I omitted to ask George about the “doing” of negotiations to take ‘time out’ and whether he was given different options to accommodate his needs. However, what George did hint at was the emotional doing of lost opportunities:

*‘...you think back saying...I could have done that I could have done this...but you just don’t have the time...because that time has gone...because you have spent time healing...’ (1<sup>st</sup> interview)*

Here, George reflects upon his bodily condition and its influence on his biography and does so through making the body a theme of consciousness. This contrasts somewhat with George’s comments above which suggested that he, unlike other participants, was able to do energy management with a minimum of reflexivity. Perhaps in the past George’s energy management required greater reflexivity because it also involved learning the capabilities of his embodied self, given his bodily condition. Everyone has to learn this and indeed repeatedly so, as such capabilities change through the life course and with what one wants or needs to do. The difference for George is that such learning was an isolating experience as the rarity of his condition meant he would have had few role models, external benchmarks or social relations in which he could compare his bodily performance with that of others on a like with like basis. This point will be picked up below when considering emotional solidarity.

### ***Giving Time to the Body***

The issue of giving time to the body as a way doing impairment was also an issue for Iris. This was not to do with energy management, but personal care needs which require the District Nurses to visit twice every second morning. This takes up

*'a big chunk of time so that time is not available for other things' (2nd interview)*

Again there are several layers of doing which Iris has to do to make this part of everyday life. The first of these was “doing” of the negotiation with the nurses over the time and day of the visits. Iris emphasised how easy this had been as the nurses had gone out of their way to be flexible and work around her commitments. Nonetheless, it is a relationship which has to be done and its ease or otherwise is contingent upon the bureaucratic system within which District Nurses operate, as well as the attitude of individual nurses.

The second layer of doing here is an emotional doing, evident when Iris commented

*'it's obviously something that I've just got to be stoical about, ...I just have to arrange my schedules so that I am not trying to give myself an impossible task to say get out at half past ten in the morning and cause myself stress' (2nd interview)*

The need to be ‘stoical’ suggests a resignation, a need to make peace with having to set aside ‘a big chunk of time’ to dealing with bodily functions and incorporating this within daily life. This involves Iris’ acceptance that the rhythm of her lived experience is now at odds with usual temporal structures. To avoid the stress this may induce, Iris’ doing will include explaining that an appointment before 10.30 is infeasible. Whether Iris’ rhythm becomes an access barrier depends upon how others respond to it. Here impairment doing slips almost imperceptibly into an instance of disability.

What’s missing here is any mention of the level of impairment doing that explores Iris’ experiences of the nurses’ practices, the way they work, touch and tend Iris’ body. This was not something which was spoken about during the interview.

Nonetheless, the concept of doing could be usefully deployed in this context. It could help to capture the mental and emotional doing of disabled people in situations where their physical bodies are repeatedly handled by healthcare professionals or Personal Assistants. Usually it is assumed that disabled people in this situation are passive recipients. While this may be the case physically, it may not be so mentally and emotionally. One participant, Diane, did hint at this when describing her technique for preparing for repeated surgery:

*'...when I go in for surgery, I kind of put my body in there but I dinnae put my mind in there. I kind of disassociate myself from it a bit and its like, just go in let them do what they have to do to me and then I get out again. It's not like it's me they have in there I don't think. It's a car going into a garage for a service kind of thing. I try not to personalise it too much.'* (1st interview)

There is an emotional doing here, in which Diane evokes the mind/body dualism to demarcate her self in order to protect it from the way in which the surface and inner reaches of her body will be handled by healthcare professionals. Diane is also doing the body by developing a narrative that her body is 'a car going into the garage' which assigns meaning both to her present and past bodily feelings and sensations. This equips Diane to deal with ongoing surgery.

The doing element in this becomes clearer when Diane explains how she has become able to disassociate her mind from the body:

*'...the last twice I've had surgery its been, maybe in the last three times its been a conscious thing [i.e. the dissociation of the body] because I'm older, I'm a lot older and I'm a lot more confident and I am better at saying to doctors and nurses how I feel and what's going on. Otherwise I'd probably cry a lot more and get quite upset'* (1st interview)

Here, doing then is something that has to be developed and learnt. As such it is contingent upon one's social status, biography and experience, enabling one to be confident and reap its rewards. Without this confidence, doing comprises distress. The broader implication here is that, for Diane at least, is that it is not desirable, perhaps not possible to undergo regular surgery without embodied doing.

## ***Enactment of Impairment***

Earlier I asked the question whether the concept of doing impairment could usefully be expanded to include the enacting of impairment through physical movement, emotions and senses. In this section I want to explore this question. In doing so it will also become clear how the enactment of impairment is influenced by the availability of different types of knowledge. Knowledge is embodied when a conscious decision is taken to enact a particular type of knowledge through the impaired body.

For some disabled people, the process of enacting impairment is explicitly and formally learnt through rehabilitation, which is rooted in biomedical knowledge. This was the case for several participants including Fraser who had ‘to learn how to live again’ (1st interview) following the traumatic onset of a spinal injury. This learning involved

*‘... more just coming to terms with living really. Transferring on and off toilets and into beds and standing in a standing frame. There was nothing wacky like learning how to crawl up and down stairs. Things which they don’t expect you to do’ (1st interview)*

It is possible to draw out two aspects of enactment. The first refers to the way an everyday physical activity is accomplished. So for example Fraser enacts getting into bed by transferring from his wheelchair to the bed while most people will enact this by walking over to the bed and sitting on it. The second aspect of enactment is only implied in the above quotation. It comprises the quality, form and technique of movement necessary in order, for example, to transfer on and off the toilet. The movement required will be contingent upon the effects of Fraser’s injury, his orientation to his body, the physical environment and nature of the toilet and the knowledge and practice of the therapists working with Fraser.

There are tensions between these contingent factors. It is biomedical and healthcare professionals which set the agenda for what and how Fraser was taught to enact his

impairment. Of course, learning how to transfer was vital, but having mastered the basics through rehabilitation, Fraser went on to teach himself 'wacky things'. This could be interpreted as a form of embodied resistance (or perhaps insistence) and/or demedicalisation. In other words, Fraser refused to limit the way he enacted his impairment and the activities he did to those prescribed and taught by healthcare professionals.

This was facilitated by Fraser's reflexive approach to his body:

*'...you've got to live life and enjoy yourself. I don't do anything I think is overtly stupid, but I am prepared to take a few risks' (2nd interview)*

On the one hand Fraser wants to maximise his activities done through his body, whilst on the other hand respecting its limits and well-being. This seems to be a continuation of Fraser's pre-injury approach when he did 'things that would stretch me' including "adrenalin rush" sports such as cave diving but only ever taking calculated risks. It is through the working out of this tension between risk and excitement that Fraser did, or attended to, his mind / body relationship. This involved research and consultation in order to calculate the risk to his impaired body. For example Fraser had to undergo a medical before diving again. The doctor placed restrictions upon the depth to which Fraser should dive. Suspecting this wasn't based on sound evidence, Fraser consulted a 'doctor friend who is a cave-diving GP' (2nd interview) who agreed with Fraser's suspicions. An interesting point here is how Fraser assesses and negotiates between different sources of knowledge and how this informs his enactment of impairment.

This suggests that the way any particular individual enacts impairment through bodily doing is influenced by a number of factors including the biological (the nature of injury), biography (sports background), social position (having the resources to do adrenalin rush sports) as well as rehabilitation.

Perhaps more mundanely, Fraser also had to develop a knowingness and practice towards his body in order to maintain his health. In the absence of sensation or movement below a certain level, this meant knowing how to do body surveillance

and interpreting and acting upon what it reveals. For example, through experience Fraser has learnt that his leg spasms are

*‘...quite a good indicator that something’s wrong. I fell out of my chair once and bent my toes and didn’t realise that my leg was bouncing up and down and didn’t realise that until I took my shoe off that I’d bent all my toes back. It probably hurt a lot’. (2nd interview)*

Fraser also needs this knowingness to avoid the complications associated with having a spinal injury. So, for example, he does his impairment by drinking a lot of fluids because the doctor at the spinal unit is

*‘...worried about kidneys and things, because that is clearly what is likely to kill me in the end’ (2nd interview)*

Here we see that doing impairment which is related to keeping well and dealing with illness, is a collaborative act which relies upon Fraser’s accumulated bodily knowing, a knowing which comprises experiential and biomedical knowledge gleaned from healthcare professionals. It also involves the doing of negotiating through the NHS.

In this way Fraser also gains more knowledge of what doing is possible through his body. This process is still ongoing. Fraser still has ‘firsts’: this year it was dealing with a long-haul flight and wandering around in a different country. One of his first ‘firsts’ was transferring when he was at home alone:

*‘I think it was interesting being sat in the house and when you transfer [i.e. from bed to chair] you’ve got to think about it because if you fall you’ve got to be able to get yourself up, because there is no one there... there is no-one there to pick you up’ (1st interview)*

Fraser’s firsts seems to be about new situations where he cannot take his body for granted, where he has to “think about” his body - both in order to do the task and to learn from the doing. He enacts knowledge and, through enacting learns and expands his knowledge. Now transferring is taken-for-granted and firsts are ‘dealing with jet lag and long flights and things like that’ (2nd interview).

Rehabilitation following a spinal injury is often considered the stereotypical and well defined process for learning the skills necessary to do impairment. So I now want to



contrast Fraser's experiences with those of Martin whose impairment was complex and unfamiliar to me. Hence Martin's doing and enactment of impairment was largely self taught.

Martin has a history of mental health issues and has had more than ten brain surgeries to treat hydrocephalus. As a result of the surgery, Martin has learning difficulties, poor memory, visual impairment and urinary urgency. Martin's doing of his urinary urgency is made more difficult by his memory problems:

*'I've got this way of focus now about the urgency problem, ... I don't go and wait until I need to go I mean I go and of course it happens with all the systems because when I arrive somewhere or when I leave this place... I pee and then I make a tiny note and that of course helps and compensating for the disability'*  
(1st interview)

Martin has developed a routine to do urinary urgency which structures his lived experience. As with other forms of impairment doing, using the toilet is something everybody does but for Martin it has to be a more considered, less instinctive process. If Martin doesn't do in this way the consequences can mean embarrassment and changing and washing clothes. Moreover, Martin has to reinforce this routine by making 'a tiny note'. More generally Martin has a series of notebooks which he always carries with him and uses to expand the capacity of his memory. So the act of physically writing in a note book and referring back to it is another way in which Martin enacts his impairment.

Another way Martin enacts his poor memory became apparent when I compared the transcripts of his two interviews. In each the same incidents and events were described using *more or less exactly the same words*. I realised that Martin was doing his memory problems by re-presenting narratives that he had told over and over again. This is how Martin explained it

*'...my f\*\*\*\*\*g disability is so hidden you know, because it is very deceptive because a) I am relatively quite articulate and b) what I've said over and over again I can say relatively quite smoothly but only because I've said them over and over and over again... people take for granted like you know if you were asked what you did last weekend. Most people it's not just a memory function matter but it's also this ability to tell a story which most people do without thinking where they are completely unconscious of ... maybe you bumped into*

*someone or you had a meal out and most people can do that and access it and verbalise it quite smoothly. I can't do that' (1st interview)*

As we saw with Una earlier, Martin's doing of his (memory) impairment is so effective that it obscures the effort involved and the limitations he experiences. He finds this very frustrating

*'because it's so hidden it's like I am screaming out' (2nd interview)*

The problems Martin and Una face because their doing masks their impairment, point to the dilemma of "coming out" as a disabled person of whether to draw attention to a non visible impairment or to "pass" as non-disabled. Passing involves withholding or concealing details or signs of impairment (or other stigmatising traits) to avoid being socially discredited (Goffman, 1990) or experiencing disablism. While Martin and Una may have the possibility of passing in some social contexts, the price they pay for this is that the doing is masked and others assume that Una and Martin can take the body for granted. As a result their lived experience is misunderstood. Interestingly, Giddens (1991) makes a similar point about maintaining "normal appearances" of the body in everyday life: such appearances require 'immense care, even though the seeming absence of such care is precisely a key feature of them' (58).

However, for Una and Martin, revealing impairment and thus coming out as a disabled person doesn't guarantee that one's situation nor their need to do impairment is understood. As we saw in Una's case, her claim to be disabled is often discredited. Passing and disclosing are equally problematic and both require forms of impairment doing.

In this section I have explored how the concept of doing could be used to capture the enactment of impairment and how this is manifested as people go about the mundane activities of everyday life. There are, I think, two reasons why further research on impairment enactment would be useful. First it would facilitate an understanding of the bodily (the physical, sensory, emotional and cognitive) expression of impairment in a way which is non-normative. In other words, it would offer a way of focusing upon what is rather than what should be. As Fraser's experiences illustrated, the

bodily expression of impairment is not purely biological. Rather it is influenced by different forms of knowledge, by cultural expectations of what a body should do and how it should be managed. So the second reason why further research would be useful is that it would provide insights into the bodily nature of impairment. Rather than seeing impairment as a bounded entity or pathology in the body as the UPIAS definition of impairment implies (see chapter one), it regards impairment as quite literally a condition of the body. This condition influences certain aspects of the bodily doing involved in everyday activities and in its relationships with the world of objects.

### ***Emotional Doing***

In the examples explored so far, a number of instances of emotional doing have been suggested as secondary to another form of doing. Here I want to look at examples where emotion is the primary “doing”. I want to pay attention to the notion that emotions too are embodied and thus ‘structure ongoing lived experience’ (Williams & Bendelow, 1998:139). Hence emotions both influence and are influenced by our engagement with the world. More significantly for my purposes, within the sociology of emotions there has been discussion of “doing emotions”: for example, Hochschild uses the term emotional work to refer to how “deep emotions” are deliberately managed to ensure they are appropriately expressed in any given context (Freund, 1990).

Within Disability Studies, Sapey (2004) has challenged the idea that the onset of impairment *necessarily* results in the individual going through a cycle of grief. He suggests that feelings of loss (or anger) may be provoked by experiencing social barriers and disablism as well as impairment. Using Thomas’ (1999) concept of psycho-emotional effects, Reeve (2004) has explored how the disablist practices of health and other care professionals can undermine the self-esteem and well-being of disabled people. In doing so she has uncovered another dimension of the oppression disabled people face in everyday life. This emotional dimension, along with emotions which disablism evokes, form an integral part of the experience of disability and impairment and may also require doing, as I will now show.

## ***Doing Grief and Loss***

Carol and Halley both spoke about experiencing episodes of grieving related to deterioration in bodily function. For Carol the doing of grief seemed to be connected with tackling the practical problems related to that deterioration, suggesting that there is a relationship between emotional doing and agency. This begins to become apparent in the following passage:

*'Well it takes a wee while to acknowledge that you have admitted to having lost something...like I mean it would be a year come May since I had my car converted to hand controls and ...so that took me about six months to a year to think I really need to do this and then once I had...so again it was me who initiated that with the GP because he had to refer me to be assessed...it's just...it takes time you know...' (2nd interview)*

Here emotional doing consists of acknowledging loss and engaging with one's feelings about bodily changes. These changes mean Carol's doing of impairment will alter. Carol will need to get used to driving using her hands instead of her feet. Also as Carol loses control over her legs her phenomenological experience of her body will differ: indeed Carol said she could feel her walking deteriorating each day.

Interestingly, in the quote above, Carol prioritises emotional doing, admitting loss, ahead of the bureaucratic doing, contacting the GP. A speculative interpretation of this is that feelings of loss can be energy sapping and require inward focus, which is incompatible with bureaucratic doing. The latter requires a certain robustness of self in order to deal with procedures in which the impaired body may become objectified and with the fear and/or reality that one will not always be treated with appropriate sensitivity. Bureaucratic doing also requires energy to make the necessary arrangements and attend appointments.

This interpretation is supported by the fact that Carol also talked about the emotional doing which emerged from doing bureaucracy

***Carol:** 'I get upset [pause] obviously [pause] you know [pause] then I give myself a shake [pause] you know maybe a few days...I never say "why*

*me?”...I really have never said that...and I am more likely to say “why not me?”...*

**RB:** *You mean...*

**Carol:** *Meaning...I am of the nature to deal with it’... (2nd interview)*

Having allowed herself to be upset, Carol changed the quality of emotional doing by giving herself ‘a shake’. This enabled her to shift into a more pragmatic orientation towards the body in order to ‘deal with it’. This meant another round of doing: gathering information, consulting mainstream and alternative health practitioners and building up a support network. In other words, ‘dealing with it’ means doing what is necessary to care for and live through a constantly changing body. This was the main theme of both Carol’s interviews, caring for her body had become a body project (Shilling, 2003).

As with Carol, Halley also talked about the need to grieve and acknowledge her losses. For Halley these losses were as much disability as impairment related. This was evident in Halley’s comments about giving up driving when she could no longer move her arm:

*‘I had that bout of depression after I came here after about a year...I just thought I couldn’t cope with being stuck in this house...and not being able to go out when I wanted to go out...I had to sort of either make arrangements and rely on somebody to say they will come and get you or something like that and you know that really depressed me...and this when I talk about grieving...you know all of a sudden you have lost something and you know you are not going to get it back... (2nd interview)*

There appear to be two forms of doings here. The first of these is living with and through depression. This may involve embodying feelings of sadness which dampen both emotional and physical energy. In turn this affects how one feels and does daily activities and the associated relations one has to form or sustain in order to do them. We see here a spiralling relationship between emotional and energy doing. Emotional doing reduces available energy, making energy management more necessary and simultaneously harder because one has less of it to manage. But reduced energy levels can in themselves provoke negative emotions because, for example, it is hard to feel happy when exhausted. Further, reduced energy also

makes it more difficult to do activities to distract one's self or do the negative emotions that one is feeling.

The second form of emotional doing Halley describes in the quote above is her feelings about being dependent upon others in order to go out. This was particularly evident when Halley talked about the fear of having to "do" everything through others to the extent that she had

*'... discussed with my children about...about taking an overdose of pills...when the time comes when I really cannot do a thing for myself...' (1st interview)*

A social worker added to Halley's fear of dependence by saying that if Halley needed care at night the only option would be to move to a residential care home, a prospect that 'horrified' Halley. This example confirms Reeve's (2004) argument that the attitudes of healthcare professionals, in this case a Social Worker, can undermine the psychological well-being of a disabled person. Halley's experience suggests that it is not only professionals who do this undermining but also the implications and interpretation of social policy. The final point to note here is that Halley told me that one of the worst things about her condition was 'living with it in your head' (1st interview). This suggests that a large part of doing both disability and impairment takes place through reflexivity and engagement with the emotions which provoke and are provoked by these states

Thus far exploring emotional doing has enabled us to consider the negative feelings disability or impairment may provoke, without giving the impression that these are inevitable, an inevitability that Sapey (2004) found embedded in the literature. More significantly the emphasis on the doing of emotions has cast disabled people as active agents in the process of moving through different emotional states, rather than as passive victims of these emotions. It also shows how emotions are part of the environment of the body and thus influence the enactment of impairment.

### ***Impairment Solidarity and Taken-for-Grantedness***

My final example of emotional doing concerns what several participants referred to as feelings of isolation related to having an impaired body. As we shall see, for some

participants these feelings were “done” or attended to by meeting others who have similar impairments - something I will call impairment solidarity. The basis for this solidarity is linked with the earlier discussion about the taken-for-grantedness of the impaired body.

This isolation was expressed clearly by Diane, who as a teenager developed an autoimmune disease normally associated with ageing. She felt she

*‘... was the only person in the world that had this so young. And there was absolutely no one that knew anything that could help so you felt pretty much on your own’. (1st interview)*

Amongst other things, there is a sense of bodily or embodied loneliness here. Perhaps part of what it means to take the body for granted is being able to check with others what’s normal, what needs to be worried about and so forth. It seems likely that Diane wasn’t able to access such feedback or include everyday body matters in her conversations with others. This increased her sense of isolation and differentness.

This interpretation is supported by Diane’s description of attending an impairment-specific group some 10 years after being diagnosed with the condition

*‘...it is definitely cathartic ...to see someone round about your same age that’s going through exactly the same as what you are going through and they just know, and you know and they know you know and you know you can talk to them and you know they are not going to think you are moaning. If you are really concerned they know they’ve been through exactly the same and can say oh yeah that happened to me or yeah I was on that medication or I got that side effect, and yeah I got my hip replaced and this is what its like and just knowing that there is going to be somebody out there that if they’ve not already experienced it they are gonna experience it. And you can call each other for support that way.’ (1st interview)*

So for Diane, attending the group was a rare opportunity to share and explore similar bodily experiences. Certain common bodily experiences could be taken-for-granted so group members could talk about the detail of impairment specific doing, such as what it feels like to have a hip replacement. This point was also made by Una

*‘...speaking with others with [condition] you can take it for granted that there is a whole layer of things they will understand without having to say it’ (2nd interview)*

However, for Diane being with others with the same impairment wasn't enough. The first group she attended one was

*'just awful. Everyone was so depressed and moaning about aching joints and stuff. And I didnae need that' (1st interview)*

What was different in the second group was that participants were of a similar young age but had an impairment associated with older people. Instead of 'moaning', in the second group members were able to engage with and processing the emotional and physical issues arising through having a particular form of impaired embodiment. In other words for Diane impairment solidarity was also a form of emotional doing.

However, the experiences of Ed and Elspeth suggest that impairment solidarity doesn't always result in emotional doing. Rather they derived support from "being with" or feeling part of an impairment specific group

*Elspeth: '... emotional support they don't give you as such...but I suppose being part of the community if you like is emotional support in itself...you know...just the very fact that you are there with other people' (1st interview)*

*Ed: 'there is very little said about each individual condition because we all know how each of them must be feeling without saying it' (2nd interview)*

This "being with" suggests two senses of taking the body for granted. The first of these is similar to that described above: while participating in the meeting Ed and Elspeth are living through the body, unaware of it because they no longer felt as if they were 'the only one', the Other or and did not have the fear of experiencing prejudice based upon bodily difference. The second sense of taken-for-grantedness is that the particularities of impaired embodiment are taken as read, not commented upon by others. However, with either meaning, the interpretation that it is the taken-for-grantedness of the impaired body which is one of the bases of impairment solidarity is at best partial. Account also has to be taken of Ed's feeling when he first went to a meeting

*'I went to the meeting and the view was terrifying... no offence meant... everyone was in a wheelchair except me' (2nd interview)*



This suggests that there is perhaps an emotional and/or cognitive process that has to be undergone before experiencing solidarity from being with others with the same impairment. Impairment solidarity is not therefore just a question of having the same impairment label. It is also about the circumstantial details.

While the concept of impairment solidarity may be new, the ideas it conveys are not. In their study of people with arthritis, Williams & Bendelow (1998) noted that attending a support group provided a “safe” haven in which people could explore their feelings about living with an impaired body. Further, as with Diane, Williams & Bendelow’s participants spoke about the importance of learning you’re “not the only one” which was key to accepting one’s changed and changing body. More generally, Goffman (1990) notes the ‘special piquancy’ and sense of ‘ease’ that emerges when people with a common stigma meet each other (103). In this section deploying the concept of emotional doing has provided the means to start teasing out the varying ways in which participants derived emotional support from doing impairment solidarity.

### ***Psycho-Emotional Effects***

One of the strengths of the concept of doing impairment is that it highlights that disabled people are continually exercising agency about how they act through the body and how they negotiate disability. However, as I have tried to show, that agency is always constrained by social factors. With my final example I want to reinforce this point by drawing upon the experience of Nathan, who talked a lot about not doing disability and impairment and the implications this has on his lived experience.

Nathan has had a neurological impairment since birth and a history of mental health issues. However, at the time of the interview he felt his biggest problem was his large size. Thus one has to be alert to how all of these facets influence his embodiment and hence his doing of impairment and disability.

During the first interview, I realised that my topic guide was based on the assumption that all disabled people use health services as it had emerged that Nathan was “not

doing” of disability and impairment, particularly where dealing with bureaucracy was concerned. For example, Nathan said he ‘should have investigated that before now’ when asked if another GP in the practice would take him on now his regular GP had retired and he ‘should have contacted the social work department’ about getting equipment that would make it easier to put on his left sock because this had been a struggle for months. He had also decided not to appeal when his claim for Disability Living Allowance (DLA) was refused despite knowing that a large proportion of such appeals are successful.

One interpretation of this “non doing” is that it is an example of resistance, of refusing to let his condition be medicalised. This interpretation is suggested by the reason Nathan gave for not appealing the DLA decision:

*‘I didn’t appeal because I felt why should I jump through hoops all the time to get what I need?’ (1st interview)*

If this is resistance it comes at a price: he can’t get a bus pass without a GP certifying his impairment and loses out financially not just on the monetary value of DLA but on all the other benefits and services for which it acts as a passport. It probably also contributes to his social isolation because without DLA and a bus pass, transport becomes problematic, especially as Nathan cannot walk very far. However, Nathan’s explanation for “not doing” was that he was just ‘drifting’. Hence, when I asked Nathan whether there were any services he felt he needed but didn’t receive he said

*‘... someone to help me focus on issues that need to be dealt with there and then, like the GP issue’ (1st interview)*

This is a telling statement, indicating some of the more subtle, less intangible “doings” that are necessary to bureaucratic impairment doing: for example being organised, articulate, confident and persistent. Yet, in contrast with other participants, these skills didn’t come easy to Nathan perhaps because of his limited “special education” and/or his social position. (Indeed, throughout the interviews, he kept questioning whether he was ‘the right person’ for me to talk notwithstanding my assurances).

A further and related barrier was Nathan's low self-esteem some of the roots of which appeared to be instances of what Thomas (2006) calls psycho-emotional disablism (see chapter one). For example, Nathan's experience of special schools led to

*'...under valuing myself and that led other kids into heckling my, my verbally undervaluing myself, it caused a vicious circle. My under valuing myself vocally, they agreed with me and it reflects back to me' (1st interview)*

It seems as if simply being sent to a special school was stigmatising and devaluing for Nathan, and this was compounded by other pupils whose verbal bullying appeared to go unchecked. A further type of psycho-emotional disablism Nathan endured was the attitude of doctors. They tended to assume that Nathan's neurological impairment adversely affected his intelligence, rather than taking time to talk to Nathan to find out his intellectual level. This problem is a common experience for many people including those whose intelligence may be impaired. However, perhaps Nathan experienced this more acutely as a result of a childhood incident when he and his mother bumped into a GP who had been involved with Nathan's impairment related care.

**Nathan:** *'The GP said to my mother " Oh he is still here, I thought he would have died a couple of years ago".'*

**RB:** *I can't imagine what that was like for a 5 year old.*

**Nathan:** *It still annoys me now' (2nd interview)*

Here we can begin to see how psycho emotional disablism influences lived experience and the doing of impairment long after the event. We see how such disablism becomes embodied: it means that Nathan has to struggle to get his left sock on each morning, it constrains the social spaces he can inhabit due to lack of economic resources and lack of confidence, it also constrains his health options. It may also be one of the factors which influence how he experiences his body day to day.

## ***Discussion***

In this chapter I have presented a multi dimensional analysis of participants' body talk primarily using Mol & Law's (2004) concept of "doing" the body. This has enabled me to put disabled people's embodied and situated lived experiences at the centre of the analysis and then consider how these experiences have been shaped by this relations of ruling (Smith, 1988). This was done by paying close attention to evidence of the dynamics between social structures and relations on the one hand and embodied agency on the other. How has this approach helped in the task of understanding impairment?

The first and perhaps main benefit of my approach is that it reveals what some disabled people have to do to and for the impaired body on a daily or recurrent basis in order to live well. We have seen, for example, how Betty has to set up and endure the air/oxygen machine each night, and how each morning Ed wonders what part of his body will work today. The reflexive body tasks highlighted here are many and varied and include those that are physical, cognitive, intimate and emotional. Yet the examples presented barely scratch the surface of what has to be done. There were more in the data but limited space prevents them being explored here. Further, as mentioned above, I did not ask participants directly about the impairment related tasks they do and suspect that more would be revealed had I done so. But doing so would have raised theoretical and methodological issues: would one want to explore impairment related doings which were no longer reflexive doings but taken-for-granted ones such as the manner of transferring from bed to chair or cleaning one's teeth with limited hand control? If so, how would one access this, given that by definition people are unaware of the taken-for-granted? Given the amount of scrutiny to which disabled people are often subjected to as a result of medicalisation (see chapter four) would questions about intimate doings such as managing incontinence be justified in a research project which would have little benefit to participants themselves?

Revealing even a limited amount of impairment doing raises some interesting tensions which underpin the experience of disability and impairment. One of these is between the ordinariness and extraordinariness of disabled people's everyday lives.

On the one hand, there were several points in the analysis where examples of doing impairment comprised tasks similar or identical to those done by most non-disabled people, albeit that the disabled person did tasks in a different or more reflexive, not taken-for-granted way, for example, Thomas and Nathan's sock putting on. In this context, Crossley's concept of RBTs is a useful tool for further exploration because it stresses the ordinariness of reflexive body work. It would also help to ensure that the ordinariness of RBTs includes the experiences of disabled people. Stressing the ordinariness of doing impairment also provides a useful corrective to some of the Medical Sociology literature, reviewed in chapter two, which considers how disabled people cope with their condition.

On the other hand, however, exploring the doing of impairment draws attention to the extraordinariness, to the quite literal extra dimension of reflexive doing which usually has to be done in addition to routines. For example, Iris must have visits from nurses every second day, Diane has to do pain and tiredness if she is to have a good night. It is this extraordinary nature of doing which I think provides a significant challenge to the orthodoxies of the social model of disability. It suggests that impairment can cause restriction which hampers social engagement and the adoption of social roles, a point a number of scholars have made as discussed in chapter one. For example it would be difficult for Iris to get a regular job given that she cannot get out before 10.30 am because of the District Nurse visit (together with other doings not mentioned here). Even with all social barriers removed it remains true that impairment doing takes time, energy and ingenuity. So too does the need to manage one's healthcare, which will be explored in chapter eight.

The third benefit from considering the doing of impairment is that it provides insights into the nature and experience of impairment in a disabling world. We begin to see that impairment needs to be understood as a condition or quality of the body the manifestation and meaning of which is always context dependent. On the one hand this accords with Shildrick & Price (1998) who argue that categories such as disability and impairment are fluid, not fixed. So Thomas has to struggle to put his socks when in the unfamiliar surroundings of the hotel, but had little difficulty in doing so at home. Fraser is a full time wheelchair user but has taught himself how to

do 'wacky' things such as climbing stairs on his backside. As well as being fluid impairment is also very much a matter of the materiality of the body, something that can be difficult to hold on to in the postmodern accounts of Shildrick & Price and which more generally often lacking in sociology of the body (Shilling, 2003).

In taking a middle path through several theoretical tensions which surround the academic understanding of disability and impairment, does the concept of doing impairment lack bite because it tries to be all things to all people? There were times when I felt that everything could be interpreted as doing, which would dilute the explanatory power of the concept. To avoid this it was necessary to keep coming back to the reflexive element of doing, to keep asking "is this the body doing to the body?" However I did stray from my focus on reflexive doing when highlighting bureaucratic doing. My justification is that I did so only when it seemed to be an integral or necessary part of reflexive doing; for example Iris's negotiations with the district nurses as part of doing her personal care and Nathan's resistance to contact a Social Worker which made his sock-putting-on much more difficult.

The significance of reflexivity to doing is not an explicit feature of Mol & Law's concept of doing. Rather I 'borrowed' it from Crossley's (2006) concept of RBTs and Csordas' (1993) concept of somatic modes of attention. Both authors emphasise the significance of culture in reflexivity, arguing that how we regard and attend to our bodies is inexorably linked to the society and times in which we live. RBTs are culturally embedded and thus their meanings can be symbolic, normative and (are often) contestable. They also change over time and vary with different subgroups of the population. So it was not surprising that culture was apparent in many examples of doing impairment considered here. For example, the context in which participants needed to do energy management was culturally shaped: the pace of life, the need to be reliable, to turn up for an appointment notwithstanding one's energy level, being active in one's leisure time are all reflections of contemporary cultural norms.

Similarly, Csordas' (1993) concept of somatic modes of attention refers to the 'culturally elaborated ways of attending to and with one's body in the surroundings that include the embodied presence of others' (138). One implication of this concept

is that the ways in which attention returns to the body and influences social interaction. For example, if a non-disabled person stares at a disabled person in the street, the latter may become aware of her body and in response “do” impairment by pretending not to notice and/or deal with the emotion that the staring provoked. Another example of a somatic mode of attention was described above when Carol felt she needed to explain to her friend her reason for not clapping. Doing becomes part of our intersubjectivity. In some ways then, the concept of somatic modes of attention offers a much broader framework for looking at doing impairment. It can take account not just what the reflexive body does to itself, but also what others do to the impaired body, and how others’ interpretation of the impaired body influences interaction.

## CHAPTER 7

### Disability Access in Health Care Settings

This chapter is about disability access in the context of health care settings. The concept of access barriers has been a key political and analytical tool used both by disability activists and scholars to deconstruct the apparent neutrality of the built environment and the social practices that occur within them (Freund, 2001). This deconstruction has revealed myriad social barriers which systematically discriminate against disabled people and restrict their life chances (Barnes, 1991). It has also revealed that these barriers are neither an inevitable outcome of impairment nor simply an accident of poor environmental design (Imrie, 1996). Rather, barriers are socially created by and ‘reflect the wider complexity of socio-cultural and political processes’ (Imrie, 1996:25). At an abstract level, these processes include the mode of industrial capitalist production (Oliver, 1990a). They also include the cultural privileging of certain forms of embodiment, namely that of the young, fit, white male. It is with that group’s embodiments, abilities and aspirations in mind that social spaces have been designed (Imrie & Kumar, 1998, Hastings & Thomas, 2005). Those with body types outside this cultural norm experience varying degrees of bodily inconvenience and exclusion. This includes but is not restricted to disabled people. To overcome this inconvenience and exclusion it is argued that universal design principles need to be adopted to create an environment which is ‘safe, aesthetic and comfortable’ for the widest possible range of embodied agents (Freund, 2001:704).

Having demonstrated that access barriers are socially created, the disability movement campaigned for barrier removal. One of the fruits of this campaign has been the Disability Discrimination Acts of 1996 & 2005 (DDA). Amongst other things, this legislation has placed a statutory duty on service providers to remove access barriers by making “reasonable adjustments” to the physical environment, policies, practices and procedures. This duty is anticipatory, that is service providers such as the NHS have to anticipate disabled people’s access needs and address them in advance of any particular disabled person using the service. In addition, as a



public body the NHS needs to “actively promote disability equality” by scrutinising all its policies and practices – not just those which explicitly deal with disability - to ensure it does not unwittingly disadvantage disabled people.

It is against this understanding of disability access and the accompanying legislation that the purpose of this chapter must be considered: to explore disabled people’s experiences of negotiating access barriers in a health care context. We know little of disabled people’s ‘interaction with the physical and/or built environment, although it is clear that they experience it in multiple and differentiated ways’ (Imrie, 1996:12). By deconstructing examples of such interaction, I want to join Freund (2001) and Hughes & Paterson (1999) in offering an embodied approach which focuses upon what happens when disabled people encounter barriers, how they handle them and the extent to which these barriers are shaped by the context in which they occur. By implication, this will challenge the idea that access barriers are *just* “out there”, divorced from the ‘attitudes and emotions we [i.e. disabled people] hold inside ourselves about our experiences of discrimination’ (Finkelstein, 1996:2). However my challenge is to the *academic* understanding of access barriers, where a more sophisticated and more nuanced approach is possible. It is not my intention to undermine the usefulness of the social model in achieving widespread barrier removal. Indeed I hope that my approach will provide useful insights into access barriers and thus enable those delivering health services to effect change.

### ***Analysing Access***

The substance of this chapter will be the analysis of data derived from two sources: the Project’s participants and my autoethnographic writings (see chapter five). My writings preceded the main period of data generation and helped to clarify that my interest in access issues lay less with the identification of access barriers *per se* and more with what happens in the moments of an access encounter. My interest also lay with whether what happens during access encounters influences and is influenced by impaired embodiment. Autoethnography has a useful role to play here because it provides a depth of personal detail and emotional intensity that it is not always possible to generate during a one hour interview. To capture this detail and intensity, I decided to present the autobiographical data as two scenarios, each of which is a

reconstruction of an access encounter I experienced in a hospital setting. These reconstructions include inner dialogue as a means of capturing the emotional and psychological dimensions integral to the negotiation of complex and situated access barriers. The description of the scenario begins the process of analysis and is followed by further deconstructions and insights.

Autoethnographic writing can be strengthened by comparing and contrasting the experiences it documents with the experiences of other people. This is what I will do here. Of course there are dangers with this: interpreting one's own experiences is less speculative than interpreting interview data, because it is only with data about one's own experiences that one can confound or substantiate it by adding new detail at any point. Further, one's ego may intervene to favour one's own story. Perhaps I have added to these dangers by structuring the chapter around the two scenarios that formed the centrepiece of my writing. However, after much experimentation, this somehow seemed more honest because it made transparent how my experience influenced my understanding of participants' experiences. It also made it more readable.

The second source of data used in this chapter was generated from the participants' interviews. The initial broad brush coding of access data was relatively straight forward. All participants were asked to describe any access barriers they had experienced when using the NHS and, in most instances it was the responses to this question which were coded *Disability access and health care*. However, three participants reported having no access problems, but elsewhere in the interview described what I would consider access problems, for example difficulties using the non emergency ambulance to get to hospital appointments. I took their initial negative response to be an indication that handling access problems becomes part of taken-for-granted everyday life to such an extent that it is not remarked upon: it's just something that's done. This meant, of course, that I looked for data on access throughout the transcripts, not just in the answer to the access question. Interestingly, unlike with all my other codes, I did not have a working definition of access, suggesting that I too took for granted that I knew what I meant by the term! As will become apparent, my meaning is a broad one: it covers difficulties with

transport, getting into and around buildings and using equipment or “fitting in” to practices which take place within NHS premises.

Having done the broad brush coding, I then asked the data questions in the manner described in chapter five. In keeping with my interest derived from personal experience, these questions concerned handling access encounters and the extent to which the health care setting influenced the nature of these encounters, how the barriers were dealt with and what were their implications.

The data which answered these questions comprised rich descriptions of participants’ embodied relationships with access barriers and the techniques used to handle them. To analyse this data further, I used the concept of doing impairment (described in chapter six) but with some refinements. I developed the concept of “doing access” to try to understand one of the embodied elements of access encounters, namely the relationship between the enactment of impairment and the characteristics of the access barrier experienced. As with doing impairment, doing access involves reflexivity, a doing to the body, with the body, in a specified context. It also involves embodied engagement with the physical environment and the world of objects found therein, an engagement which is often mediated through social interaction. Then, at some almost imperceptible moment, the doing of access becomes access handling. This concept describes the embodied action disabled people take to avoid, resolve or minimise the effect of access barriers in their everyday lives. Again, as with doing impairment, handling access assumes disabled people’s agency, albeit an agency that is constrained (but sometimes enabled) by social structures.

I will present the doing and handling access data alongside the first autoethnographic scenario. This scenario was written before developing the two concepts of doing and handling access although they are implicit within it. This posed a presentational dilemma: do I re-analyse my scenario using the concepts or do I treat it as a fixed text? The latter has the advantage of showing how my thinking has developed from personal experience, through critical analysis of the literature, to the use of new tools to analyse the experience of others. It is the latter approach that I have chosen.

However, sometimes I have used the concepts to clarify points in the analysis of my experiences.

The second and smaller half of this chapter will explore what I will refer to as clinical access. This is the subject of my second scenario where it refers to access issues that emerge during the process of diagnostic testing or treatment. These issues were highly context dependent and required bespoke solutions. Clinical access barriers did not figure greatly during the interviews: they were hinted at by two participants and formed the main topic of one of the pilot interviews. One can speculate as to the reasons for this: it could be that clinical barriers are only a problem for a small number of disabled people whose impairments are enacted in a very particular way, because participants didn't think this type of barrier was an access issue and thus did not mention them, or it could be that discussing these barriers required a level of detail that participants did not want to disclose. The latter was true in my case and so it wasn't something I spoke about when I was interviewed.

### **Scenario One: What's in a Bed?**

*It's a planned admission. I'm sitting in the corridor of the ward with my PA (Personal Assistant). The nurse, who's just going off duty, points the way to the bay where my bed is now ready. We find it easily and say a tentative hello to my three bay mates.*

*Arriving at my bed, my heart sinks. It has none of the features I need in order to transfer on to the bed and move around once in it. A jumble of thoughts and emotions come to the fore: self chastisement because it hadn't occurred to me to ring the ward beforehand to check they could provide what I needed; sadness at the realisation that with my new more restrictive bodily ways I should no longer assume I could cope with less than ideal situations even with a PA. Yet I am buoyed too, knowing K and I make a good team when it comes to managing tricky access situations. But I'm worried that, while I know the nursing staff will help, they may not do so in the way that I want. I am unashamedly fussy about these things. It is my body after all.*

*I sit silently with these thoughts until the night nurse comes in to introduce herself. I take a deep breath and seize the moment. It's now or never I tell myself to get over my unease at having to ask for what some may consider too much.*

*The nurse 'gets it' straight away and goes in to action so quickly I almost don't have time to be relieved. She negotiates with my neighbour to swap beds. Her bed being electrically operated will enable me to sit up and to adjust the bed height to my chair for the purpose of transferring. Then the nurse spots what I haven't: my bed space has no curtains, a problem with the laundry apparently. No doubt realising I will need help in bed and therefore a degree of privacy, she asks a second woman to swap bed space with me. I'm impressed and heartened, the nurse seems to be handling it all matter-of-factly, as if its part of the routine. Perhaps it is routine. I do feel a slight awkwardness with respect to my bay mates. Will they see me as grabbing the goodies, the electric bed, the curtained spaced, as causing upheaval just as they had just settled in a strange, anxiety ridden environment? Somewhat ineptly, and probably more for my sake than theirs, I try to explain why I need these things and the precariously and often shadowy boundary between being able to cope with a given environment or not.*

The first point I want to draw from this scenario is to consider how the bed came to be constructed as an access barrier. The intrinsic qualities of the bed played some part of this. Had it been an electrically operated bed, there would have been no access problems. But context too played a role. By context I mean the material features of the space and the social practices which happen within it. These practices influence how the space is used, the purpose and structure of its routines, and the roles and relationships of the people within it. Had I been a visitor or healthcare professional working in the ward the bed would not have been a barrier. As a patient, I gradually became incorporated into the nursing routines: waiting outside until the bed was ready, being shown to my bed, the night nurse coming with medication. Amid all this purposeful activity, the decision to allocate one particular actual bed (as opposed to matching an abstract bed to an abstract patient by a bed manager) was probably totally arbitrary. There were two electric beds in the four bedded bay so I had a fifty fifty chance of being allocated an inaccessible bed.

Another ingredient in the construction of the bed as an access problem was the way my impairment was enacted. Had I been allocated the same bed two years previously there would not have been a problem. Now I do not have the strength and control over one of my arms so I can't pull myself up. But this was not the only aspect of my embodiment which played a role here. My embodied agency was also involved and this had several elements; my (low) tolerance levels of the phenomenological experience of my body in less than average circumstances, my

confidence to articulate my needs and my expectation that access barriers should be removed wherever possible. All these elements were shaped by my social position. Perhaps more significantly they were also shaped by my understanding of the social model, for how the body is experienced phenomenologically is influenced not only by bodies in spaces but also by (embodied) consciousness (Freund, 2001). While the social model may be disembodied, its precepts and transformative powers can nonetheless be embodied. Being embodied, it influences my perceptions of material features and practices within social space and enables me to identify some of these as barriers and then gives me a basis from which to handle them.

Nonetheless, it is with a certain degree of trepidation that I handle access, I transform the interplay of these social forces - embodiment, the hospital context and its practice, as well as the non electric bed – into an access encounter. The encounter then is the social interaction prompted by the naming of the barrier, a rare moment of foregrounding a feature of the environment and my relationship with it. In the processing of doing so I bring (unwanted) attention to my embodied self, making me feel out of place, uncomfortable at having to disrupt the flow of events and the pattern of the relationships with my bay mates. But the interaction between the nurse and me became the dynamic for change and resolution of the problem. The nurse listened, responded to my needs with great sensitivity and removed the access barrier. What was it that enabled her to do so: personal qualities, hospital policy, professional training or a combination of these? Certainly the hospital context also played a part because the equipment I needed was readily available.

What I have drawn from this scenario is that *some* access barriers are contingent upon the coming together of a number of factors: the qualities of material objects, social spaces and the practices that happen within them, embodiment and agency. At a critical moment these forces shape an access encounter in which social interaction occurs. It is this social interaction which forms part of access handling. At this point it is useful to recall Thomas' (1999) social relational approach to the social model. This restates UPIAS' definition of disability – the imposition of a restriction of activity – but emphasises that this is a specific form of an unequal social relationship between impaired and non impaired people. Thomas goes on to point out that this

relationship occurs at a number of different levels and in a variety of social contexts. With regard to access, at the most abstract, access barriers emerge from a capitalist mode of production (Oliver, 1990a). It is literally built into the environment through the interaction between land values, planning and building regulations and their enforcement (Imrie & Hall, 2001). But it can also occur and be enacted at the moment when a particular disabled person, at a particular moment, encounters a particular access barrier, in a particular context. The relationships between all these particularities are changed, re-ordered by the way the encounter is handled by each party. In some instances, those changes are positive, the barrier, if not removed, is negotiated either physically or through interaction or through both. The latter was the case in the scenario. In other instances, the handling may be botched and so undermine systems put in place to facilitate access. This can be illustrated by a participant who described how a nurse made ‘a right pig’s ear’ of hoisting her. This was despite the fact the hoist was made available, that the staff said that they had been trained in using it and that the participant suggesting her PA could help.

This line of argument that access barriers are contingent and multilayered is much messier than the simplicities of the social model which says ‘we are disabled by society not our bodies’ (Shakespeare & Watson, 2001). As such, it is politically risky because it can blur the issue about who is responsible for resolving access issues. If we admit that impairment has something to do with access then people will say “we can’t do anything about that” and so barriers remain. But a way round this is to identify two different types or categories of access barrier, the macro and the micro. What distinguishes these is the degree of contingency and whether the solution required is general or individual. This is best illustrated by example. A flight of steps can be considered a macro access barrier, constituting a barrier not just for me but for many with mobility impairments and in just about every social space in which there are steps. Therefore they are not very contingent and they require a universal form of solution, the provision of a ramp, lift or alternative entrance. But the same cannot be said about hospital beds which can be categorised a micro access barrier. Although I am probably not the only disabled person who needs equipment attached to a bed, the configuration of equipment I need may well be particular to my needs.

Distinguishing between macro and micro access needs becomes pertinent when considering the NHS's anticipatory duty under the DDA. One can argue that macro barriers can *always* be anticipated and removed or bypassed by means of a reasonable adjustment. Micro barriers too can be anticipated, but indirectly: it is not always possible to anticipate the actual barrier or the most appropriate way of dealing with it for any individual. However, what can be anticipated is that some disabled people will have specific needs and systems ought to be in place to enable healthcare professionals to respond to these appropriately in the moment of the access encounter. This is exactly what happened in this scenario. The question then becomes: what training and support do healthcare professionals need to enable them to respond in this way?

### ***Anticipating Access Needs in Healthcare Settings***

To further explore this point about what type and level of access needs should be anticipated in health care settings, I want to draw upon the experience of one participant. At the time of interview, Iris had had a recent spinal injury, was a wheelchair user and had twenty four hour Personal Assistants. She was also a regular health care user due to ongoing kidney and bladder problems. It appeared that one aspect of Iris' doing of access was grounded in having to make an explicit judgement about the situations where it was necessary for her to alert people of a certain type of access need in advance of an appointment:

*'Within the NHS ... I don't ask questions like if they have a ramp because I always assume that there will be a way in ...but they might not [have] other specialist things that I might need... when I go to the clinic for spinal injured patients ...they're always going to have a hoist somewhere lurking behind, but as I say the place at [the clinic] which is smaller...' (1st interview)*

Iris assumes all NHS premises will have wheelchair access but feels that a hoist is a 'specialist thing' the availability of which depends upon the type of facility. Believing the clinic to be small, Iris handles the access by phoning ahead to request a hoist. What did Iris feel about having to do this?

*'Well in an ideal world you wouldn't have to do that [phone ahead], in an ideal world somebody would say to me 'don't worry Iris [the clinic] will have the facilities for you' ...but we don't live in an ideal world...' (1st interview)*



Here, Iris foresees the possibility of the NHS being able to anticipate and meet her access needs, but only in an ideal world. In the mean time she gets on and handles access.

Gigi, another wheelchair and PA user, appeared to have higher and more general expectations about how the NHS should deal with access compared with Iris:

*'In a health care setting they think that the provision of facilities for disabled people will be x or y, but they never think about a, b, c, d, e, or f, because we are all different. And some of us are more different than others...they should think of a way of accommodating anyone with any impairment.'* (2nd interview)

Unfortunately, I omitted to ask Gigi whether she felt all disabled people's needs should be anticipated and if so what ideas did she have about achieving this in healthcare settings. . In terms of the DDA, ultimately this is something that will be decided by negotiation and case law. In the meantime, when handling access, disabled people will have to judge where, when and for what they can rely upon the anticipatory duty. These judgements could become a collective force for change because the more micro needs that disabled people expect to be anticipated and met, the greater the pressure on service providers to do so.

To turn back to Iris, although she rang to request the hoist when she arrived

*'I could see that they weren't expecting me to be in a wheelchair... they didn't make a big fuss, somebody just went whooshing off to find a hoist'.* (1<sup>st</sup> interview)

The phrase 'they weren't expecting me to be in a wheelchair' is interesting. It could simply be a reference for her access needs. But it could also suggest that Iris felt wheelchair users were unexpected, out of place. However, it's not clear whether this has anything to do with the hospital environment in particular or being excluded from social spaces generally. Nonetheless by ringing to request the hoist, Iris announces her (impaired) existence and avoids the awkward moment when others register that one is not what they expected. Hence 'they didn't make a big fuss' could have been a mark of relief. This reminds us of the symbolic importance of the DDA requirement to anticipate: it indicates that it should be expected that disabled

people are out and engaging in the world. More pragmatically, requesting the hoist can be seen as the outcome of doing access. This involves reflexivity, the embodied self thinking about its bodily needs in a particular space and then taking action to ensure those needs are met. The possibility of embodied agency means Iris can minimise her dependence upon the vagaries of the small clinic but she can't escape that dependence altogether. As Thomas (1999) pointed out, disability is characterised by an unequal power balance between impaired and non impaired people, which is weighted in favour of the latter. Despite requesting the hoist, it wasn't there when Iris arrived. Iris' effort was wasted, but she didn't mention that: perhaps from her point of view all that mattered was that there was a hoist - the encounter was ultimately successful.

So far the access scenarios considered have altered or enhanced the environment through the provision of equipment. However, for some participants it was the other way round, they had to "do access" by adapting the enactment of impairment to the environment in which they found themselves. This was the case for Joel, a wheelchair user, when using his local health facility:

*'They have steep ramps. It is a compromise basically. So the access to the reception area of the dentist is brilliant. The access in the consulting rooms is appalling...the ground floor rooms are too small for the wheelchair and the dentist chair. I am fairly agile so I can sit and do the twists and turns necessary to transfer'. (2nd interview)*

Here then, it is Joel's agility which enables him to "do" access to the dentist's chair. It enables him to twist and turn in contrast to his usual, probably less effortful, way of transferring from his wheelchair to another surface. Joel makes clear that he sees this as a compromise: he decides to handle this access barrier by making his embodied self yield to it. He does so by reflecting upon what his body can do in the situation and what he is willing to put his body through. But this decision is constrained by the lack of alternative options due to the shortage of NHS dentists in Edinburgh, the lack of information about which dental surgeries are accessible and Joel's preference to use a local surgery. This example also demonstrates that access barriers are rarely "all or nothing" situations, rarely is a facility totally accessible or totally inaccessible. Rather there is a huge spectrum between these two poles and

disabled people constantly make decisions about if and how to handle any particular access barrier.

Given this spectrum, it becomes important to acknowledge the embodied costs and consequences of access solutions which are a compromise or fall short of best practice. This needs to become part of the process of assessing whether an adjustment or alternative service is reasonable from the point of view of the disabled person requiring access. I now want to consider one element of these consequences, namely those which influence the physical and emotional aspects of embodiment. This is an issue that has been discussed in the literature from several different angles. As we have seen in chapters three and six, Reeve (2002 & 2004) has used Thomas' concept of psycho-emotional effects empirically to highlight the ways in which disablism affects the psyche and erodes self-esteem. More specifically in the context of access, Imrie & Kumar (1997) found that for some disabled people, feeling powerless when faced barriers, was given as a reason for not going out. Hence feelings and memories of previous encounters become embodied and influence how barriers are handled in the future.

It has also been argued that barriers do not just restrict social participation but also serve as symbols of the exclusion and inferior status of disabled people in contemporary society (Anderson & Kitchin, 2000, Edwards & Imrie, 2003). This symbolism is reinforced in the moment of an access encounter which forces attention back to the impaired body. This awareness may also incorporate uncomfortable or painful bodily sensations which are caused as the body negotiates and compromises with the material world (Paterson & Hughes, 1999). In some instances, such sensations become inscribed in embodiment to the extent that they become taken-for-granted and only noted when they are absent, that is when some aspect of access relationship improves (Zola, 1991). As a way of capturing and highlighting the embodied consequences inadequate access, Anderson & Kitchin's (2000) use of the concept of dignity is helpful. It can act as a marker, a reminder that access arrangements which compromise dignity must be challenged: an example of an "undignified" encounter from my own experience was having a long conversation

with the practice nurse about my incontinence on the pavement, as the GPs surgery had been made temporarily inaccessible.

In many instances the emotional impact of doing and handling access is subtle, fleeting and relatively easy to absorb into the ebb and flow of lived experience. For example, in the hospital bed scenario, whilst swapping the bed and bed spaces was welcome physically, it nonetheless made me feel somewhat awkward towards my bay mates. I feared they would see me as disruptive and demanding. It also feels difficult to convey the critical importance of factors such as bed height to those for whom an insignificant detail because getting into bed is a taken-for-granted task. Similarly, Lesley, a family carer for Kate who is a wheelchair user and has learning difficulties, spoke of her irritation when the location of Kate's appointments was changed. This meant a third person had to accompany them to appointments and had to stay with Kate at the entrance while Lesley went to find a parking space. What was hard, Lesley commented, was that no explanation was given for the change and that no-one realised the difficulties it caused. Perhaps greater upset was caused by the consequences of the ambulance service's policy of refusing to take wheelchairs on board. Frances' impairment means that she has frequent emergency admissions to hospital and being without her wheelchair results in

*'...negative reactions from nursing staff because I have had to ask for more help...It makes me feel much more vulnerable and much more tearful as well which isn't me.' (1st interview)*

One of the implications here is that in terms of the phenomenological experience of embodiment, a wheelchair has greater significance than the means of getting from A to B. Wheelchairs are highly individualised to meet the needs of a particular user. As such they are the bases from which one engages with people and the material world. Thus they influence the physical, emotional and existential aspects of embodiment. Hence without her wheelchair, Frances 'isn't me'. In addition to the emotional cost of not having one's own wheelchair, there is the sheer inconvenience of access handling. Frances has to arrange for a friend to ferry the wheelchair to hospital. This also involves the expense of a taxi. One of the strands which link Frances, Kate, and Lesley's experiences is how one's emotional well-being is contingent on

the detail of policy and practice. Yet this is seldom realised, because the doing and handling of access is invisible from all except to those who do it. Highlighting this doing and handling should be another criterion by which to assess the reasonableness of adjustments or alternative provision.

A final point I want to make is that the process of access handling itself can be emotionally demanding. For example Iris, who we met above, hinted at this:

*'I kind of find that the way to cope with that is .... Don't get wound up it's not going to do you any good'. (2nd interview)*

Here it is as if Iris had worked out intellectually the best way to handle things ...not getting wound up...and was now working on putting this into practice. This suggests that another element of handling access is learning how to handle one's embodied self, to protect it from the hurt and stress of repeated access encounters. In some instances the need for self protection is more important than handling an access issue in what sounds like the best way. This was Elspeth's experience when it came to one particular access issue in a health care context, namely managing urinary urgency if there is a long wait before being seen at clinic:

**Elspeth:** *[People] can't know that if I need to go to the toilet...I need to go now... I need to go RIGHT NOW...[I ask] "where's the nearest toilet"...and they say,... "its just away at the end of that corridor and just go up the flight of stairs"...and I am like... "NO you don't understand"...but then it's not people's fault...if it is something that's invisible it's not their fault...you have to be...you have to learn to be open and say...I require this because...*

**RB:** *So it comes down on you to explain...*

**Elspeth:** *Yes I think a lot of times it does...because if we don't explain how do they know?...*

**RB:** *But once you explain do you usually get a helpful response?*

**Elspeth:** *I don't usually explain...*

**RB:** *So what happens?*

**Elspeth:** *I just struggle...*

**RB:** *And you don't explain because...*

*Elspeth: Because you don't want to look at the look in people's faces...or.. "Oh I am really sorry" ...in a nice big loud voice...It's a very...it is a catch 22...again it's a catch 22 situation...' (2nd interview)*

Elspeth felt it best to be open and frank about her needs, to make the invisible apparent, otherwise she couldn't expect help. So Elspeth felt part of what she had to do to handle access was explain her access need to others in order to get appropriate help. But doing this requires drawing attention to a bodily function in a way which may offend social convention. For Elspeth, this also means revealing that she is a disabled person since the enactment of her neurological condition isn't always visible. Elspeth prefers not to do this because it requires "emotional doing", dealing with 'the look on people's faces', the loud voices which makes her the centre of attention. This is perhaps an example of Elspeth suddenly being read as The Other, of being all the more threatening because she appears to be 'like them'. Ultimately, this threat and the attention are too much for Elspeth, so she decides to 'struggle', to handle the problem by relying upon her ingenuity in her moment of need. This too is risky for if she doesn't make it to the toilet, not only will her identity be discredited (Goffman, 1990) but also there will be much doing impairment to be done.

In this section I have explored the ways in which disabled people do and handle access. This exploration has challenged the idea that disabling barriers are *just* objects 'out there', existing independently of any disabled person. Rather barriers always have an external and internal dimension because they are embodied. The embodied element of access barriers and their associated encounters it not just a reference to the way an impairment is enacted, its relationship with space, and objects within it. It also includes emotions, sensation, memory and agency.

### **Scenario Two: Clinical Access**

*I had an ultra sound scan on my bladder to investigate the causes of my incontinence. I had to drink a litre of liquid beforehand so worried about being wet but had planned for that eventuality as far as one can.*

*I transferred on to treatment couch ok. The nurse was helpful, moved machinery out the way and positioned the bed to the optimum height. These little things make such a difference. My PA assists. Strictly speaking there's no money in my care plan to cover assistance when I'm out during the day, yet*

*it's so essential. I wouldn't want total strangers helping me with transfers in unknown territory. It's too precarious.*

*The radiologist did the scan. I managed to get in a good position on the bed so was comfortable so didn't start the spasm off. Suddenly the radiologist tells me to go the toilet and then come back for a second scan. I panic. I don't know what's happening and by the time I get it together to ask what's going on, the radiologist has gone. The nurse gets my PA from outside. I begin to explain my difficulties to the nurse....*

*I can't use a public toilet as can't transfer on to it and no good hoisting me on because I wouldn't have the balance to sit once on. I use a female bottle when I'm out and in extremis but it's tricky and not always successful. And there's another problem. Transferring is energy intensive and my fatigue threshold low. There's no way I can get off the couch and then back on again for a second time. It might sound silly to say this, that I only have a very finite amount of energy but must do. Pushing beyond that limit is to enter risky spasm territory.*

*The solution we come up with is to use the bottle on the examination couch. Nurse sits behind me so I can lean against her, PA holds the bottle. It isn't really a success, I'm too tense in this awkward position. I will finish the job, as it were, once the scan is over.*

*The radiologist comes back, does the scan... "here's the problem". I brace myself. There was a big notice outside saying radiologists can't discuss findings, must make an appointment with your doctor for a fortnight's time to get the results. Why is he telling me? Does that mean it's something serious?*

*With all this in my head, perhaps it is not surprising that I didn't really take in or question what the radiologist was saying: access issues so quickly overwhelm. He said something about my bladder being too large and not being able to empty itself. Back home it dawns on me: I knew my bladder wasn't empty at the time of the second scan. But that was an access problem, the result of using the bottle on the bed. It wasn't a medical problem just an artefact of the test itself... wasn't it?*

One of the most commonly mentioned clinical access issues is that of transferring from wheelchair to examination couch (Begum, 1996, Campion, 2003, Kinrade 2003, Tighe, 2001, Thomas, 2001). However, this scenario suggests that clinical access can be more complex than not being able to transfer and that one of its key characteristics is uncertainty. There are a number of layers of this uncertainty. The first of these is the uncertainty surrounding the process of a diagnostic test or the procedure. This uncertainty is something many people face when undergoing such procedures but I think this has particular ramifications for some disabled people. In

my case, I was unable to plan to handle access because I didn't know what the scan would involve. When the radiologist told me to use the toilet, I panicked. I was overwhelmed with anxiety about how I could do impairment, how through reflexivity I could plan a way to use the toilet in an unfamiliar environment. I added to this anxiety by assuming it was my responsibility to deal with the access issue, perhaps in part because I did not want to discuss my intimate needs with a strange man. Hence all this anxiety prevented me from having a conversation with the radiologist about the best way of dealing with the situation. With the benefit of hindsight – and to prefigure an argument I am going to make below – this was a lost opportunity to reduce uncertainty by giving the radiologist information about how I enact my impairment when using the toilet. In terms of the emotional element of embodiment, what happened to me in this scenario is similar to Elspeth's experience explored above: emotional reactions got in the way of handling access in the way we wanted.

The second layer of uncertainty was that neither the radiologist nor myself knew how my embodiment would respond to what the test demanded of it. This is to enter cyborg territory, 'the couplings between organism and machine' (Haraway, 1996:83). Previous certainties about the boundaries between the natural and the artificial become decentred and destabilised. When the second scan revealed that my bladder had not emptied itself, was that revelation "natural" concerning the inner workings of my body? Or was it 'artificial', a revelation that appertained to the test situation, to my having to urinate into a bottle whilst being propped up? Here we begin to see some of the ironies of the biomedical approach. Diagnostic procedures are designed to increase the medical gaze, to bypass the subjectivity of the patient to reveal what's "really" happening in the body. Yet what "really" happens with the body is never experienced in the abstract, I can never empty my bladder outwith the enactment of my impairment and the environmental circumstances which together make it so difficult to use the toilet. So perhaps the artificial was actually the natural here, the second scan revealing what happens to my bladder when I attempt to empty it in a particular environment.



The question then became whether the social barriers which influenced the internal workings of my body needed to be acknowledged, to be made explicit. My fear was that the radiologist would look at what happens when my bladder empties in situ, but interpret it as what happens to my bladder in the abstract. In other words, my fear was that he would overlook the social. But how could he have done otherwise because at no point in the procedure did he ask any questions? To him I was little more than an aberrant bladder. Hence I regretted not explaining to the radiologist my difficulty with using the toilet. Had I done so, it may have been possible to discuss what role access issues played in my incontinence. Later, I did discuss this with other healthcare professionals but I never felt I could adequately convey the scope of the difficulties I was experiencing. Perhaps going to the toilet is such a taken-for-granted bodily experience, and a private one, that it is hard to explain the detailed ways in which it can become problematic. Everyone I spoke with insisted there was something ‘medical’ going on, but the basis for saying so was never clear. The uncertainty continued. There is another biomedical irony here. As we saw in chapter three, biomedicine interprets the impaired body as abnormal. However, throughout the procedure, indeed throughout the whole diagnostic process, it was as if I were treated as ‘normal’, no-one stopped to enquire as to my impairment needs, my ‘abnormality’ as they would see it, regarding using the toilet.

There is another possible reading of the scenario, and that is as an illustration of Shakespeare & Watson’s (2001) argument that it is impossible to know where impairment ends and disability begins. Was it disability or impairment that made it so difficult for me to empty my bladder on the bed? Was it disability or impairment that caused my incontinence: disability because of all the years I had to ‘hang on’ to go to the toilet until a PA was around or traipse round to find an accessible toilet or impairment because something medical had happened during my illness to cause the problem? Did I want the problem to be interpreted as social so that it could be solved through barrier removal – a 24/7 care package and the installation of the equipment I needed to access the toilet – or a medical problem to be solved by medical means? Perhaps the most interesting point to make about these questions is that they were on my mind throughout the time I experienced the problem. Again I take this to be a sign that I had embodied the social model, it was part of my psyche

to analyse my own experiences with reference to the impairment/disability dichotomy. In retrospect, this didn't serve me well because there was no definitive answer to the questions I was posing. Perhaps the social model offers certainties where none exist.

From my experience, clinical access issues entail two features: not knowing what a test might involve and the absence of any opportunity during the procedure for discussion of any disability concerns. This suggests that it would be useful for healthcare professionals to be aware that clinical access needs may arise and to discuss these before the test begins. They also need to be willing and able to problem solve with the disabled person at each stage of the test.

Clinical access was also an issue discussed by David, a wheelchair user. For him these access problems occurred in many settings and seemed to emerge from the interrelationship of three factors: first, David's enactment of impairment, which means he cannot intentionally control his movements and that lack of control can be exacerbated in unfamiliar situations, second, how this is interpreted and handled by the healthcare professional, and third the physical circumstances of the encounter. For example, David described the moments before being anaesthetised:

*'It's having to go in to a strange anaesthetic room and say 'will you hold me?' But it can be read as a kind of baby's 'I'm scared, hold me' kind of thing. And you're not, you're overcoming the practical problem of actually not being able to lie flat on a table of that width. I mean my right arm was just as likely to shoot way out there unless it's held in place and so on and yet it's so often interpreted, unless you're lucky, as a kind of "I'm scared of anaesthetics help me". And it's not that at all.'* (Pilot interview)

Here then, one layer of the barrier is the narrowness of the operating table and the effect it has on David's movement. With insufficient space for his arm, David loses control of it. Similarly, being unable to lie flat, to yield to the table, increases the risk and fear of falling. Taken together, these appear to adversely change David's sense of embodiment. There may be little that can be done about the width of the table, given the requirements of theatres. Yet this is compounded by the second layer of the barrier: namely how David's request for assistance for his body to be held to reduce the unwanted movement is misinterpreted as being scared and

childlike. While being ‘scared and childlike’ may be how some adults are when about to undergo surgery, for these qualities to be (wrongly) ascribed to David implies a lack of respect for who he is, his embodied self and for what is involved in his doing of impairment. It is another form of indignity. In this situation, the option of David explaining what is going on is just not possible: you are *‘not exactly at your best when you’re lying on a theatre table about to be put under’*. Perhaps David’s awareness was focused upon what was happening to his body and therefore talking might have been particularly difficult.

The way to remove this clinical access barrier, David feels, rests with the healthcare professional’s ability to assess what the barrier is:

*‘Unless they can diagnose what’s actually going on, you’re not going to solve many of the actual disability issues...they must be able to diagnose “why is this man jumping around in this trolley when he shouldn’t actually be doing that?”’*  
(Pilot interview)

This diagnosis is not a medical one but a social one. To remove the barrier healthcare professionals need to be able to interpret signs of David’s impairment, how it is likely to be enacted in relation to different physical spaces or objects found in hospital contexts. Perhaps what prevents this happening is two fold: first that healthcare professionals will not have a (medical) understanding of many impairments and second, what understanding they do have may be abstract, an understanding of what is going on with the body but not of how this can be manifested in particular environments or circumstances. This is similar to my experience with the investigation of my bladder problems suggesting that a characteristic of clinical access barriers is the general lack of understanding of the lived experience of impairment, something discussed in chapter three.

A second form of clinical access barrier David talked about was healthcare professionals’ attitudes towards disability. Since the early 1990s, the General Medical Council (2003) has stated that respect for, and an understanding of, the social and cultural environments in which disabled people live as a necessary outcome of medical education. Yet this lack of understanding still seems to pose a widespread barrier (see, for example, Campion, 2003, Scottish Consumer Council,

2005, Thomas, 1997 & 2001). One example of this barrier occurred when David was undergoing a course of treatment and several of the healthcare professionals treating him had

*'tendencies to talk through my wife. They would not talk to me. And if she said "no talk to him", they couldn't understand me.'* (Pilot interview)

Whatever the intention, it is hard to interpret the result as anything but a failure to recognise David's personhood, with all the implications that has for his dignity and well-being. As David pointed out, the situation was made more complex because for some of the healthcare professionals, English was a second language. This perhaps made it more difficult to understand David's impaired speech. But it is hard to see this as a language issue alone. If the professionals were unaware of his difficulty it would suggest a problem with her communication skills, she wasn't considering the implications of being unable to talk with the patient. Equally, had professionals been aware of the problem then presumably they should have taken action such as asking a colleague to assist or asking David if it would be acceptable for his wife to facilitate the conversation. Moreover, it should have been regarded as an issue of management of the service to ensure that he was allocated an appropriately skilled professional. All this impinged upon David's treatment insofar as he was consequently unable to explain why he wanted and needed the treatment

*'... trying to explain that to someone who doesn't have any disability awareness is just not on. And that was the fundamental problem'* (Pilot interview)

When it came to handling clinical access issues, David felt

*'I think the ball really is in their court. If they hit it off in the first minute well, then I can carry it on. It's like a service ball in tennis, if they serve me a good one, I'll respond. If it's a bad one, such as the dental hospital, it's just going to get worse and worse. So no, I don't think I'd say that I have a strategy worked out. I know it's going to be important, but I don't really know how I'm going to achieve it.'* (Pilot interview)

This highlights that the ability to handle access issues is always constrained. For David, one of those constraints is the enactment of his impairment, that control of his movement is affected by other aspects of his embodiment such as whether he is

nervous or under stress. This in turn is affected both by the context and the quality of the relationships available within that context and both of these factors are outwith the control of David in clinical arenas. Indeed, perhaps it is the nature of clinical access barriers that they are often unpredictable and thus disabled people's ability to handle them is circumscribed. While the barriers are equally unpredictable to the healthcare professionals nonetheless they need to know that such barriers may emerge and be open and willing to respond creatively and with humanity. This is an area where further research is needed to assess the scope and nature of the barriers which emerge and the strategies used to deal with them.

## ***Discussion***

Drawing upon the data, this chapter has explored a small number of the many access barriers experienced in health care settings. I have tried to identify the varying elements of such barriers and, through an embodied approach, considered how disabled people experience and deal with such barriers. This breaks with the social model tradition which sees barriers as external and which the disabled person confronts in an isolated and isolating moment in time. That tradition also locates the root of barriers at a high level of abstraction, namely the social and economic forces of capitalist production. What can be learnt from a localised, embodied and context specific approach?

The first learning point is that the relationships which emerge during an access encounter play a significant part in determining its outcome. In both clinical and non-clinical healthcare contexts, many access needs are micro ones, that is, highly individualised situations which require health professionals to respond sensitively and creatively in the moment. As we have seen in this chapter, this already happens but perhaps consideration needs to be given to ensuring that this happens as a matter of routine. As one participant pointed out, unless this happens, the DDA will only benefit the 'fit male paraplegic' whose needs are mainly macro ones requiring standard solutions.

The second learning point is that the impact of access barriers is sometimes more complex and personal than the exclusion from and loss of social opportunities which

the disability movement has been so effective in highlighting. Thomas (1999) has drawn attention to the psycho-emotional effects of dealing with barriers and disablism. The indignity that David experienced when healthcare professionals spoke to his wife instead of to him, Iris' injunction to herself not to be stressed out and Frances' upset because the ambulance would not take her chair can all be seen as examples of psycho-emotional effects. But consideration also needs to be given to the role emotions play in shaping or constraining disabled people's agency when handling access. This was Elspeth's experience when she decided not to ask directions to the nearest toilet. That example also demonstrated that much can be at stake when handling access, that it is rarely just a matter of ensuring one's immediate needs are met: what an individual has to do negotiate a barriers and the way the materiality of the barrier is changed, have consequences for the embodied self which go beyond the achievement of access in the moment of encounter. To ask for help meant Elspeth had to reveal her disabled identity which she was not prepared to do. Similarly, in the second scenario, access during the scan had significant implications for the management and treatment of my incontinence. When much is at stake in an access encounter, its handling can become emotionally charged.

An embodied approach to access can be used to capture some of the subtle ways in which emotions both influence and are influenced by access encounters and handling. It can also be used to investigate how bodily sensations and movement are implicated in access encounters. This is something that I have barely touched upon here. It is implicit in Joel's 'twisting and turning' to get into the dentist's chair and David's difficulty in controlling his movement in unfamiliar or physically awkward circumstances. It is also implicit in my second scenario where I do not dare to get off the examination table because I know I would not have had sufficient energy to get back on to it, as the test required. As with emotions, bodily sensations and movement both influence and are influenced by doing and handling access. As my questioning of the causes of my incontinence suggest, years of handling access barriers in using the toilet had literally shaped my bladder, making it overlarge and damaging its function. The social had become the biomedical, disability had become impairment.

A further and final learning point, and one I only became aware of during the writing of the chapter, is the difficulty of explaining access needs to others. We saw this in Elspeth wanting to be open about her needs, in David having to rely on healthcare professionals' interpretation of his uncontrolled movement and how it is related to the context, and my wishing that I had talked to the radiologist about my toilet difficulty. It is difficult to untangle what the issues are here. One element seems to be straight forward; as far as micro access needs go, these often cannot be known unless they are articulated by the disabled person. But at another level it is also about one's self being understood by others notwithstanding one's bodily needs or appearance. If David's movements are misinterpreted he is seen as a frightened child, if Elspeth explains she needs the toilet 'right now' she will have to confront 'the look in other people's faces'. Without explanation there is a risk to identity and personhood. But explaining, too, is difficult. With regards my incontinence, I was desperate to be able to make the healthcare professionals' understand the minutiae of my toilet access needs. But as much as I tried, I never felt they really appreciated the situation. This became a barrier in itself and a source of frustration. There seems to be much scope for further investigation here. Is this problem widespread, does it interfere with everyday relationships between disabled people and non-disabled people, is it rooted in the fact that access needs usually relate to activities in which non-disabled people don't have to think about what their bodies are doing as both the task and the doing of it are taken-for-granted? These are questions for another time.

## CHAPTER 8

### Healthcare Encounters

This chapter will present an analysis of disabled people's health care encounters. It will explore how disabled people "do" healthcare, in other words how they manage the process of accessing and using the NHS together with the way they handle relationships with healthcare professionals. This will complement the analysis presented in chapter six by considering whether participants use or would like to use the NHS to support and enhance their doing of impairment. Similarly, it will extend the analysis of the previous chapter by looking at how disabled people handle their micro access needs in hospital settings.

The data upon which this chapter is based comes from participants' descriptions of their health care encounters. These comprised a substantial chunk of data: as one would expect, when participants were asked about healthcare experiences they described and reflected upon particular healthcare encounters. This revealed much of what is right about the NHS as well as highlighting where improvements could be made. Deciding upon my angle of interest in this data was difficult. Initially, the broad brush code "managing use" use.

To analyse this further the technique of "asking the data questions" was used again. The questions related to participants' development and use of expertise to access and utilise the healthcare they needed to do impairment. These questions were informed by debates about the nature of patient expertise within the sociological literature generally (see, for example, Anderson, 1996, Oeseburg & Abma, 2006, Prior, 2003, Tyreman, 2005). More particularly the questions were inspired by current policy initiatives aimed at supporting people with long term conditions or impairments to develop expertise in managing their conditions in particular (see below). However, while the expertise questions revealed the different forms of expertise participants deployed, ultimately the concept of expertise as an analytical tool proved inadequate for gaining an understanding of participants' use of the NHS. I want to consider why



it was inadequate by discussing current policy about developing patient expertise. This will provide a useful backdrop to this chapter.

Recently, the Scottish government in conjunction with the Long Term Condition Alliance in Scotland (LTCAS) launched *The Self Management Strategy for Long Term Conditions in Scotland* (2008) (which I will refer to as the Strategy). This is broadly equivalent to the Expert Patient (Department of Health, 2001) initiative developed in England and Wales. Whereas the English version refers to expertise as a means of developing self management skills, the Scottish one focuses upon self-management itself, seeing such management as a means of improving people's quality of life. Both these policies address the question, if somewhat obliquely, of what the NHS can offer those with conditions which are chronic, incurable and often untreatable. Similarly they acknowledge that often disabled people know more about how their condition affects them than healthcare professionals, particularly those within primary care (Jessop, 1996, Wilson, 2001)

The aim of the Strategy is to ensure those 'living with long term conditions have access to the support they need to successfully manage their condition' (LTCAS & The Scottish Government, 2008:7). The main form this support is to take is various forms of information giving and patient education. Support will also be provided by improvements in the co-ordination of health and social care services and by making them more responsive to individual need. It has been suggested that if self management is to be effectively encouraged then healthcare professionals' practice must be rooted in a social medicine. Further, such practice has to be capable of understanding and engaging with the lived experience of disabled people and the diversity of social contexts in which chronic illness and impairments are experienced (Bury, Newbould & Taylor, 2005, Tyreman, 2005).

However, while the rhetoric of the Strategy is empowering this may be difficult to translate into empowering practice for two reasons. These reasons also highlight why the concept of expertise is similarly problematic. The first factor is that while the Strategy lauds self management and the expertise this requires, it may have the unintended effect of shifting such management further under the ambit of medical

control and surveillance. Currently, many disabled people have developed their own self management skills, what I would call doing of impairment, outwith the medical gaze (Badcott, 2005). Moreover, it could be argued that in some cases they have done so despite healthcare professionals: an example of this in the lack of instruction given to one participant, Betty, about how to use her oxygen/air machine (see chapter six). To be successful, the Strategy will need to find way of building upon people's self taught and contextual knowledge. If this doesn't happen there is a risk that people will be deskilled in the same way that Illich (1990) argues that healthcare service undermines self care. As it is, the Strategy assumes that healthcare professionals are the "real" experts as it will be they, for the most part, who will teach people how to self manage. Just as the patient's view is an artefact of the doctors gaze (Armstrong, 1984) which leads to the doctor creating the patient's subjectivity, so too the self managing disabled person may become an artefact of health and social care professionals. So while promoting self management may involve a flow of information between healthcare professionals and individuals, it will not necessarily lead to a transfer of power (Wilson, 2001). Hence disabled people may be 'subtly coerced into self-care and self management processes, so to prevent deterioration and reduce the demand on resources' (139).

The second reason why the Strategy's empowerment rhetoric may be undermined in practice is that while it talks of the need to form partnerships between healthcare professionals and disabled people, it asserts that self management is ultimately the individual's responsibility. So it considers neither the support someone would receive if they refused or could not self manage nor the impact of biographical or social constraints upon doing self management (Chapple & Rogers, 1999). Yet self management without adequate resources and support can be profoundly disempowering (Wilson, 2001). Similarly, there is no discussion of social changes which might facilitate self management and improve quality of life. Unwittingly the Strategy does make this point. It uses a full page photograph of a man on a mobility scooter accompanied by someone riding a bike, with both wheeling along the sea front. On top of the picture there is a large heading "What is Self Management". This picture and heading can be interpreted as a quality of life activity made possible through self management. Yet while scooters may make a substantial contribution to

quality of life, they are not routinely provided through the NHS Wheelchair Service so have to be privately purchased. Hence in this instance self management is contingent upon having sufficient private income to buy equipment.

From this overview of the Strategy, I want to draw out the reasons why the concept of expertise was inappropriate to drive my analysis. As used in health policy, the concepts of expertise and self management are abstract, isolated from the context in which it is derived and exercised. This obscures the questions of in whose interest expertise is being developed, its purpose and how it is mediated by social constraints and professional power. More academically, for my purpose the concept is devoid of any sense of embodiment. Yet implicit with policy documents is that expertise is an embodied skill exercised upon the body.

Having realised these shortcomings with using the concept of expertise as an analytical tool, I went back to my data. Reading it through, I considered developing a concept comparable and compatible with doing impairment and doing access as used in the previous chapters. The obvious candidate was “doing healthcare”. However, that too lacked any sense of the body and could be limited to looking at the administrative arrangements involved in using healthcare (there is much in the data about that!). It also lacked any sense of purpose, of what motivated and constrained participants’ usage of the NHS, or develop relations with healthcare professionals in a particular way. I then came across the perhaps obvious but often not stated argument that people consult a healthcare professional to take care of the body (Mol, 2008) and, I would add, the self. Hence people “do” healthcare to take care of the embodied self. Here then was a tool which may facilitate an analysis of how participants used or wanted to use the NHS to support their own care taking of the body. This would enable exploration of the ways in which participants access support for self management. It would also provide a way of looking at what participants expected from the NHS in terms of the services it offered and the ways that it responded to disability or impairment related health needs.

Revisiting data revealed a great diversity of ways of doing healthcare to take care of the body (this will be abbreviated to doing healthcare for reasons of space). The

examples of doing healthcare presented have been selected to explore, exemplify or refine the concept of doing healthcare. This will help to assess its usefulness or otherwise. The analysis of each example will try to take account of:

- The embodied reflexivity that may underpin the decision to use the NHS at a particular moment in their lives.
- What enabled or constrained participants to contact the NHS in the way that they wanted
- How participants handled the process of getting healthcare professionals to take care of the body in the way that the participants wanted
- The embodied consequences of participants getting or not getting the support they wanted

The analysis will be presented under three headings:

- Doing healthcare by accessing health services
- Doing healthcare in hospital wards
- Doing healthcare in relationship with healthcare professionals

These headings or categories are cross cutting. For example, all doing healthcare occurs in relationship with healthcare professionals. Yet the examples considered under that heading are those where the relationship itself is the focus of doing whereas in the examples explored under the other headings that relationship is a means to an end.

Some of the data demonstrated that participants wanted the NHS to support their doing impairment but did not constitute doing healthcare because the support they wanted was not forthcoming. In other words there was no healthcare for participants to “do”. These data are clearly significant in relation to the support participants receive to do impairment. It is this data will be presented first. However, there was also data about health care encounters where there was little doing of healthcare because the participant felt the care was timely, appropriate and accessed easily and barrier free. This data isn’t presented because there is little to say about it. The

drawback is that what follows extenuates the negative, but hopefully in a way which is constructive.

### ***Unmet Expectations of the NHS***

A number of participants felt they did not receive sufficient healthcare support. As we shall see, the type of support participants wanted was somewhat ill defined, nebulous. Instead they had a general expectation that the NHS should support them. These expectations seemed to be grounded in their sense of embodiment and a medicalised culture in which the NHS is regarded as the obvious port of call for those with body troubles.

Burt, who experienced a sudden onset neurological condition in his middle years, seemed to expect that because of his impairment he would undergo regular medical surveillance. Indeed the key motif of Burt's interview was that following the acute stages of his condition he was effectively abandoned by the NHS:

*'...once they had finished with me that was it, never again. At the time I thought possibly, and maybe 6 months down the line they would ask me back to [hospital] for a progress report or a year, but never ever happened.'* (Pilot interview).

There seems to be several layers of this expectation. First it seemed to be linked with Burt's sense of embodied experience following the onset of his condition. Burt talked much about the physical enactment of his impairment: his dragging leg, his hand that 'was more or less useless', his difficulty with pronouncing certain words. To me, these enactments of impairments were almost imperceptible, invisible. Perhaps in the moments when Burt was aware of his body, its feel and limitations, this invisibility was isolating and added to his frustration, which, for example, led him to be enraged by dropping a spoon. From this perspective, the expectation of surveillance may have been a hope to gain an acknowledgement of his bodily experience. Yet Burt did have bi-monthly blood-pressure checks at his GP surgery but these clearly didn't meet his expectation of being supported by the NHS.. A reason for this may be because his surgery is large and it hasn't been possible for

Burt to get to know one particular GP or nurse. This suggests that current prioritisation of improving access to GPs at the expense of continuity of care is a policy constraint which contributes to Burt's feeling of abandonment.

A second and related layer to Burt's expectation concerns his capacity, the possibility of improving function. For eight months Burt had out patient physiotherapy. Then he

*'...reached a point where they had decided that they could do no more for me, and that was it, I was dropped. I've never heard a word since.'* (Pilot interview)

Again Burt felt abandoned, perhaps powerless in the face of professional judgement irrespective of whether it was correct in terms of NHS policy and clinical judgement. Yet being an "old Labour" man Burt said he would never complain about the NHS. Doing healthcare is constrained by values and belief, but some forms of doing are more constraining than others. Nonetheless Burt did healthcare by consulting a private physiotherapy notwithstanding a limited income because he felt the physiotherapy was still 'doing a great deal of good'. Perhaps for Burt this was a form of taking control, refusing to be passive in the face of what Burt experienced as bodily limitations.

However, I think there is a tension embedded in Burt's feelings about ongoing physiotherapy. On the one hand, Burt felt he had reached a stage in his recovery where his body functioning was 'as good as it gets'. On the other, five years on, Burt 'continues to do to this day' the exercises the private physiotherapists gave him, along with other bodily activities which he devised himself. Perhaps this continued reflexive doing to and with the body is now less about improving function and more about the embodied satisfaction of taking exercise. Doing exercises could be interpreted as both a means of keeping well and as a way of reducing the chances of a reoccurrence of an acute episode of his illness. Perhaps it is also Burt's way of making health a pursuit (see chapter two). At some points the boundaries between keeping fit, pursuing health, improving impaired function become indistinct. There is also a danger that when a disabled person does these things they are seen through a medicalised lens

A third layer to Burt's expectation of receiving NHS support seems to be connected with his medicalised view of disability. Burt commented

*'my wife...was never at any time given any advice, training or back up on how to deal with a stroke patient. But I felt later, that she should have been given some instruction, you know, about how to deal with what are quite a few side effects of the stroke. One of them I'm afraid to say is uncontrolled rage at the slightest thing' (Pilot interview).*

By referring to himself in the third person, Burt seems to confirm the argument that with the onset of impairment or chronic illness, people tend to objectify their bodies. This can be a means of distancing the Self from the affected part of the body, a body which momentarily seems beyond control (Bury, 1982, Toombs, 1992). However, Burt goes further, objectifying not only his body but also his Self. He then casts body and self as the object and subject of the medical gaze. From this position, Burt feels his wife needs medical support to 'deal' with him as if he were an object, rather than support to relate to him as a subject. It is this, I think, that suggests Burt medicalises his physical and emotional bodily condition. Speculating, this may be a response, a means of containing the fearful embodied experience of 'uncontrolled rage' and its implications for Burt's partner. Burt's biography may have also inclined him to a medicalised view of disability. He grew up when disabled people weren't a visible part of the community and disabled people were thought to be looked after by the medical establishment. This view may have been reinforced when Burt was hospitalised.

Burt's experiences hint at the embodied and cultural complexities which lay behind his expectation of greater support from the NHS. As someone with an adult onset degenerative condition Peter, too had unfulfilled expectations. He felt that the NHS

*'...should have offered help to me. I shouldn't have had to request it. They should have been there to reassure me.' (1st interview)*

This suggests that Peter had a medicalised and culturally informed view that the NHS would be there to offer support for disabled people automatically, look after them without being asked. Perhaps this view predated the onset of Peter's impairment and shaped his expectation that the NHS should provide reassurance. The issue of

reassurance was a refrain during both of Peter's interviews. However, its meaning shifted and looking at these meanings gives insight to Peter's expectations of the NHS.

At one stage, Peter seemed to use the term reassurance in connection with prognosis:

*'They gave me the name of what the condition was. Didn't give me the background, or any reassurances as to what might happen. What to expect. Or anyone to contact.'* (2nd interview)

We get a sense here of how Peter felt let down when given his diagnosis over the telephone by a medical researcher Peter had never met. At one point Peter reported saying to the researcher 'you can't leave me like this', which was a form of doing healthcare, of desperately trying to protect the embodied self in a moment of isolation and turmoil. Without any information, Peter had and continues to have contradictory expectations. He knows the doctors cannot tell him what to expect because his condition is rare and takes many forms. But the emotional need for knowledge, for reassurance as to the future remains. Similarly, Peter wants a prognosis but doesn't want to know about likely problems before they arrive. This suggests that wanting reassurance through having a prognosis was a possible way to counter the profoundly destabilising experience of embodying the knowledge that the body will degenerate in the near future but knowing nothing more than that.

Fortunately, by doing healthcare outwith the NHS Peter discovered two sources of reassurance: doing impairment solidarity (see chapter six) and using an alternative health practitioner. The practitioner

*'...was prepared to discuss and talk things through. He was just prepared to ask me how something affected me, not what it should affect.'* (1st interview)

Like many who turn to alternative health practitioners, Peter found someone with the space and interest to engage with Peter about his embodied, lived experience.

A further meaning Peter imputes to reassurance concerns the lack of available treatment. For example

**RB:** *Were there other ways that you would like them to be more reassuring?*



***Peter:** In my opinion it is a double edge sword. I am really pleased that I am not on medication but in my opinion they were too quick to say that there is nothing that we can give you. (1st interview)*

Again Peter recognises that what he wants is contradictory: he is relieved that he doesn't have to take medication yet wants his condition to be treatable. By saying doctors were 'too quick' to rule out treatment suggests that he does not quite believe them, a point Peter reiterated several times. At one stage he suggests that the reason they haven't given him treatment is because he 'gives off the wrong signals' that is because his enactment of impairment isn't always apparent, visible. This resonates with Burt's experiences and suggests an issue of legitimacy, of a fear of one's embodied experience and anxieties being diminished or dismissed because bodily and emotional doing of impairment isn't apparent. Phenomenologists argue that the body is the ground level of all experience (Hughes & Paterson, 1997). Thus to experience the world through an impaired body and for that to be hidden to others, is to have an inescapable risk of having one's primary bodily experience of the world misunderstood by others. Yet perhaps this doesn't really capture the issue of invisibility because visibility of the enactment of impairment is no guarantee of understanding by others either.

In one sense, Burt and Peter's expectations beg an awkward question for me. Are there clinical grounds for the support that they need and if so can that support be justified in the context of the NHS where resources are scarce and demands high? Of course I am not in a position to answer this. However, what needs to be flagged up for further debate is whether Peter and Burt's expectations can be interpreted as a desire to share responsibility for self management and if so what sort of services would constitute such sharing? Before considering this I want to look at a similar strand of the data.

A number of other participants spoke about the lack of medical interest in them and their condition. More specifically, six participants felt they would like a regular "health MOT". For example Thomas, who had a congenital neurological condition, repeatedly made the point that no healthcare professionals took any interest in him:

*'the interest of the GP's has not improved at all because obviously they regard Cerebral Palsy as something they don't know much about, not much can be done about and therefore no point in spending any money on their patients' (1st interview)*

It is difficult to understand fully if and in what ways Thomas felt his body would have been better cared for if healthcare professionals had taken greater interest. However, it may have been related to Thomas' fear of his condition deteriorating:

*'I was told I was stiffening up, a GP once told me that although my condition was static, the effects of it would worsen over time and I would end up in a wheelchair. Not terribly reassuring.' (1st interview)*

As a result Thomas felt that

*'it would be nice to be invited in for a check up occasionally' (2nd interview)*

This check-up, Thomas felt, should involve a functional assessment because what lay behind Thomas's fear was not deterioration of his bodily condition per se but the implications this would have on his quality of life. In turn, these implications related to his struggle with his current daily doings of impairment and an assumption that if his impairment got worse he would still not receive any daily living support. In this situation having access to social model thinking and indeed advocacy may provide a viable alternative to the lack of medical support and options.

This expectation for a health MOT may also be related to broader social trends. One participant Betty, notwithstanding her six monthly check ups with the consultant, felt that if people had a serious illness

*'someone could just follow up and make sure that you are eating properly, that you are coping properly, do you need more exercise you know, to arrange for you to go swimming or get you out if you are feeling depressed... I live alone ...I am looking, I think, to the National Health Service to sort of give me the comfort and the care you know that I am looking for'. (1st interview)*

The implication here is that with changing patterns of family life which result in more people living alone the NHS should share responsibility for self management and extend its reach into everyday life.

In this section, an analysis has been presented that suggests some participants wanted greater medical input and had unfulfilled expectations of the NHS and healthcare professionals. This may be related to aspects of their embodied experience interpreted through the deeply culturally embedded biomedical model of illness. For my purposes this raises two questions.

The first of these is whether it is useful to interpret these unmet expectations as evidence that some disabled people want further medicalisation of disability and impairment? On a simple understanding of medicalisation as the extension of medical power into more and more areas of everyday life (Zola, 1983) I think it does. On one level, this conflicts with the critique of medicalisation by some Disability Studies' scholars, discussed in chapter four. However, this does not necessarily imply endorsement of medicalisation of disability in other areas: for example Peter was very critical of the way some doctors fulfil their gate keeping role. Further, it could be argued that it is precisely because disability is medicalised that people turn to healthcare professionals for support even though such professionals may not be best placed to provide it. In other words the impetus to medicalise a problem is no guarantee that it will be identified and resolved by the medical profession (Conrad, 1992).

This brings me to the second question, whether the NHS is best placed to meet the needs participants identified. A number of commentators have argued that healthcare professionals find it difficult to engage with the emotion, isolation or suffering that some people with impairments or chronic illness face at some points in their lives (see, for example, Cassell, 2004, Frank, 1997,2002, Kleinman, 1988). This seemed to be borne out by the experiences of several participants. Further, it is not just disabled people who want healthcare professionals to listen and empathise with them and provide the reassurance and support participants identified (Green & Griffiths, 2003, Kleinman, 1988, Lupton, 1997a). If the policy shift towards supporting and enabling people to take responsibility for self management is to be successful, consideration needs to be given to how the emotional needs generated by such management can be met (Mol, 2007). One possibility is to increase access to proven alternative therapies that can offer body work which gives space to

embodiment, that is to an understanding of the body which includes the mind and spirit as well as the fleshy body (Twigg, 2000).

### ***Doing Healthcare by Accessing Health Services***

Providing equality of access to health care is a major concern for all with an interest in health policy, with the challenge being to create a system which provides ‘the right service, at the right time, in the right place’ (Rogers quoted in Gulliford, 2002:187) for all citizens. In this section, the focus on accessing healthcare is much narrower. In the context of exploring doing healthcare to take care of the body, it is about how disabled people’s impairment and embodied agency influences the ways in which they use the NHS.

For two participants, accessing healthcare was problematic because there were no specialist services dealing with their conditions. For Una the only treatment for her condition was graded activity courses. However, her GP said there were no such courses locally. Hence Una had sole responsibility for managing her condition which mostly involved doing energy management and doing healthcare by accessing alternative therapies when she could afford it. For Agnes, a middle aged woman and former healthcare professional, things were more complex. Agnes had health needs which were the cumulative effects of the enactment of impairment on her musculo-skeletal system, as well as new problems associated with the re-emergence of her underlying condition acquired through an acute illness in childhood. However, ‘there is nothing’, no services or specialists in Agnes’ condition. Moreover, in a resource and time limited system Agnes is never ‘assessed as a whole being’. For example, she was referred to an orthopaedic specialist and physiotherapist for knee and hip pain but neither had the time or understanding of Agnes’ condition to do a holistic assessment or look at her back where the pain may have been coming from.

How then can we understand the interacting layers of Agnes’ experiences? The first layer concerns the impaired body: the very adaptability of the body which enabled Agnes to maximise function in relationship with the environment, has now become a problem. Agnes has ‘moved abnormally all these years’ and now somatically experiences this as pain. The second layer involves reflexivity, feeling and thinking

about the pain, doing the anxiety of not knowing where it comes from or what it means, and then deciding that to take care of her body she needs to seek help. Third is the doing of healthcare. While there are medical interventions which may benefit Agnes, none are available locally. As a result Agnes has to carefully handle her relationship with the GP in order to secure appropriate referrals, by attending multiple appointments and by researching her condition. Agnes also does health by being involved in an impairment specific group which lobbies politicians for appropriate services such as a multi-disciplinary clinic dedicated to her impairment. As well as the energy required to do healthcare in this way, there is the frustration of never being seen as a whole being, of being an anomaly within a medical system which thrives on identifying and treating abnormalities. But there are moments of emotional connection too,

*'the orthopaedic man...I got a glimpse of somebody who did care and wanted more for his patients and couldn't get it' (Pilot interview).*

This also reminds us of the constraints healthcare professionals experience.

In contrast with Agnes, there are specialist health services for people with Fraser's impairment. However, for him doing healthcare has to begin with using reflexivity and accumulated bodily knowledge to decide whether the problem is related or exacerbated by his spinal injury. This is not always obvious. For example on one occasion Fraser's leg became swollen so he went to the GP who diagnosed an infection and prescribed antibiotics. However, Fraser

*'didn't trust the GP to have picked up that this was just an infection or something else and wanted to make sure it wasn't a DVT or something to do with my spinal problem' (1st interview).*

Yet this lack of trust wasn't absolute, the GP had given Fraser some reassurance:

*'He was down to earth and you know he explained why he didn't think it was a DVT and thought it was an infection. And that seemed fair enough' (1st interview)*

One gets a sense here of Fraser weighing up his need to be protective of his bodily well-being, his bodily knowledge and wanting to respect the GP's expertise. In the

end, he decided to obtain specialist advice from the spinal unit because he had to contact them about another problem: Fraser sat with his leg elevated to help it heal but didn't realise this put extra pressure on the base of his spine, damaging the skin. Fraser was reassured when the consultant confirmed the GP's diagnosis but also felt it was opportunity

*'...just to get more knowledge. I think that is quite important. Because the internet is one thing...But you have people who are a lot more informed on these things' (1st interview).*

For Fraser getting more knowledge makes doing healthcare easier especially when that knowledge is personalised. The consultant uses expertise to interpret the knowledge to apply it to Fraser's particular circumstances. It is this expert interpretation that Fraser feels makes a significant difference between information from a consultant to that found on the internet which is abstract and not tailored to Fraser's specific circumstances.

If Fraser's doing healthcare is influenced by the nature of his impairment and his bodily knowledge, then Carol's doing is influenced by being a former healthcare professional who has an explicit commitment to using the NHS proactively to 'keep myself as well as I can'. Keeping well is different from managing impairment or self management: the former suggests striving for embodied well-being whereas the latter is disembodied and focused on the impairment as a discrete entity. To keep well Carol took the advice of her colleague, a GP, to

*'...take ill health retirement and to look after myself... because he said nobody else will... and its very true...' (1st interview).*

The implication here is that working constrains the possibility of looking after one's self, her embodied response to impairment. Usually in this context, work is seen as a constraint because of the stress it causes or that it depletes energy and thus distracts from social life. For Carol, however, work was seen as constraining because it would allow insufficient time to doing healthcare because she is 'in contact with the NHS all the time'. Not working meant Carol was able to do healthcare in a number of ways including: researching her condition, experimenting with alternative therapies, attending appointments and condition management courses. This was in

addition to doing impairment and disability such as making her house accessible in anticipation of becoming a wheelchair user.

The ways in which Carol did healthcare were influenced by her biography, particularly her healthcare background. It meant that she tended

*‘...to look at or think of a way to get in touch with so and so before this gets any worse...’ (1st interview)*

In other words, Carol often interprets what’s happening to her body through a biomedical lens and combines this with her insider knowledge of the NHS to decide who and how to contact in any given situation. For example, if Carol wants to see a neurologist she knows that

*‘...if the GP makes a referral you go back to the bottom of file...whereas at least if we have a specialist nurse...that’s one way... its not jumping the queue...its getting to them sooner rather than later...’ (1st interview)*

Carol recognised that her insider knowledge gave her privileged access to health service and expressed concern for those who don’t know how the system worked.

In some senses, there is a tension between Carol’s intensive doing of healthcare and her knowing ‘conventional medicine has got nothing to offer’ those with her condition. For example, Carol saw a rehabilitation consultant and although he wasn’t able to help, she wanted to remain on his caseload. When the consultant refused Carol said:

*‘I am not going to go away... you know...so who’s gonna look after us...’ (1st interview).*

Carol too seemed to have an expectation of the needing to be looked after by the NHS similar to that of Burt and Peter. However, it is different insofar that they had no contact with the NHS whereas Carol does. Of course this difference may reflect different health needs for even though an underlying condition is untreatable, medical interventions may help with symptoms. But there may be something else happening here as well: that people gain security from knowing how or who they would contact in the event of having an impairment related health crises. So for

Carol, being on the rehabilitation consultant books meant if her walking deteriorated in the way she felt it would, the consultant would arrange specialist physiotherapy.

This argument about the security derived from knowing who to contact can be made by looking at the positive comments participants made about specialist nurses, whose specialisms are often condition specific, for example, the rheumatology nurse. Carol, together with Ed and Elspeth, emphasised the accessibility of the nurses and the reassurance they gained from knowing that they could ring the nurses in the event of a crisis. For example, Ed took 'great comfort' knowing he could ring the nurse whenever needs be. This is consistent with an evaluation which found that one significant benefit of having MS Specialist Nurses was providing a named contact within the NHS (Forbes et al, 2002). Interestingly, however, one participant with this condition gained the same sense of comfort from knowing her adult children would always get the healthcare she needed as quickly as possible. This again highlights that family structures influence how people think about healthcare usage.

Participants also valued specialist nurses because they could short circuit NHS bureaucracy, bureaucracy which was both one cause of doing healthcare and a barrier to it. For example, Ed said:

*'...the last time I phoned up the MS Nurse I said, "I have got spasms" ...she asked a few questions and said "I will have a word with the consultant and he will arrange an appropriate prescription via your doctor". So that is a fast track you know'. (2nd interview)*

The specialist nurses also seemed to be a source of practical advice. Through home visits to people with the same condition specialist nurses built up an extensive knowledge about the everyday world of those living with the condition. This enabled the nurses to provide people with a sense of what constitutes "normal" bodily doings for those with the condition. Hence Elspeth commented that the nurse

*'doesn't just deal with what's happening, she gives you a probable scenario... [This means] you are not surprised when something happens...and also you can say well...that's reasonably normal and there's nothing to panic about' (1st interview)*



This sounds very similar to the reassurance the Peter wanted. It also highlights that the combination of biomedical knowledge with that gained through insight into the lived experience enables specialist nurses to mitigate some of the bodily uncertainty which comes from having a progressive impairment. Perhaps it is not surprising then that for Ed, the nurses played a similar role to impairment solidarity (see chapter six):

*‘...it was wonderful to talk to someone who understands’. (2nd interview)*

This section has explored some of the factors which influence the way disabled people do healthcare in terms of accessing appropriate health services. Impairment related health needs and the configuration of health services are obviously important in this. But, as we have seen so too is participants’ bodily knowledge, their ability to research and personal resources influences their attitude towards seeking NHS support and enables them to make contact with it in quite a sophisticated way (Watson, 2003). This inevitably begs the question of what happens to those people for whom social constraints and structural disadvantage make doing healthcare very difficult. This was illustrated by the experiences of Alan, who has learning difficulties and a neurological condition, who was reluctant to go the GP due to the cost of paying for prescriptions.

### ***Doing Healthcare in Hospital Wards***

Being a hospital in-patient is rarely a pleasant or wanted experience for anyone. Sixteen participants talked about hospital stays, six of whom described negative incidents where their impairment related needs were ignored. These could have been analysed in terms of handling access. Such handling involves the participant negotiating with the aim of removing or reducing an access barrier during the moments encounter (see chapter seven). However, the six incidents are particular cases of access handling, relating to nursing care practices in an institutional setting, the ward. In this setting, one mark of professional nursing practice which differentiates it from other social care practices, is nurses’ ability to identify and respond to a range of needs without the individual having to articulate it (Davis, 1988). Where this occurs one would expect there would be minimum need for doing healthcare and this was the case for a number of participants. The interesting

question is what happens when individual impairment needs go unnoticed in hospital wards, in what circumstances do participants have to doing healthcare in the ward setting? More pertinently for my purpose, is there something about the relationship between a disabled patient's embodiment, care practices and the ward environment which makes it different from access handling in general?

As a frequent healthcare user, Joel is used to doing healthcare and feels that this ensures his embodied self is appropriately cared for. But Joel did not feel this during a hospital stay after planned surgery unrelated to his impairment. Joel used the pre-admission appointment as an opportunity for doing healthcare, by discussing with the nurses what access equipment he would need on the ward. Using his reflexivity and bodily knowledge, Joel also discussed the possible effects of the surgery on his impaired body. These included not being able to transfer and balance in his manual wheelchair because the surgery involved cutting through his chest muscles. Unfortunately this doing had no apparent effect, a reminder that however much emotional time and effort put into doing healthcare, its success is always contingent upon the attitudes and acts of others and the systems within which they work. While in Joel's situation the problem may have reflected the communication difficulties within a large bureaucracy, it nonetheless jeopardises the hospital's compliance with the DDA as Joel's request for equipment could be interpreted as a claim for reasonable adjustments.

This failure to respond to Joel's requests for reasonable adjustments was compounded by an apparent neglect of his nursing needs immediately after major surgery. For example:

*'I don't think they had any training on pressure, or pressure control. So I had to literally ask to be turned..' (1st interview) 'I would have expected them to be more aware of the fact that I was more prone to pressure sores than Joe Public' (2nd interview)*

To have to ask to be turned represents an instance of healthcare doing when the embodied self is subsumed by post-operative pain, medications and unfamiliar bodily sensations. Yet this doing was necessary in order to protect the very integrity of the outer layer of Joel's body. The pertinent question here is what happened to nursing

practices? If professional nursing practice is about identifying need (see above) then one would have thought that nursing routines would include both pressure care for most patients after major surgery and a systematic way of identifying those who, like Joel, are 'prone to pressure sores'. Of course, one of the limitations of this study, which is very apparent in this section, is that it does not include the voices of healthcare professionals and the barriers to good practice which they experience. This is a substantial limitation here, particularly as another participant had a similar problem but in a different hospital. Fraser repeatedly asked the nurses for a pressure relieving mattress yet it never materialised. Fraser raised the matter with the consultant who was

*'...quite keen that I complained. I didn't because I'd got other things to do and I just wanted to forget about it.'* (1st interview)

What's interesting here is that the consultant passes responsibility to Fraser to complain, expecting Fraser to undertake further doing of healthcare. Yet arguably had the consultant had greater authority over the nurses and could have dealt with the matter quickly, informally and discretely. Fraser's response, having other things to do, is a reminder of the need to set limits to disability and impairment doing so one's life does not get subsumed it.

To return to Joel's situation, on the fifth day after surgery he was told he would be discharged. Yet when Joel was put in his wheelchair he could not balance as the surgery had effected his enactment of impairment. Joel had anticipated this may happen and discussed it during the pre-admission appointment. Again this doing had no effect. So Joel started doing healthcare again when he found out that no home care had been arranged. At this stage Joel 'had to literally stick up for my rights' (2nd interview) and refuse to go home. Had he not done so the hospital would have sent Joel home without being able to enact his impairment in his normal way, so unable to function. In this situation, without support, Joel's embodied self would have been vulnerable on the emotional, cognitive as well as the physical level.

Joel had an explanation for the apparent rush to discharge him:

*They just hoped that I would fall into the general category of an able bodied person and be out in five days to comply with government targets.’ (1st interview)*

If Joel’s interpretation of what happened is correct, it suggests that nursing practice was mediated by the pressure to meet targets to an extent that nurses did not assess or meet his needs. The implication would be that the very ways in which the fleshy bodies of patients are touched or left untouched by the equally fleshy bodies of nurses, are constrained by the structures through which health policy is implemented. More generally, these targets are likely to be grounded in a notion of a non-disabled person or “typical case”. Subsequently there is a risk that disabled people may be regarded as problematic cases and this may adversely affect quality of care. Ironically, once staff realised Joel would not be discharged within the target time, attention was focused entirely on his impairment needs. This has a positive outcome as Joel was transferred to a rehabilitation unit in which he found the treatment and care beneficial.

Whereas Joel had his impairment related needs neglected, Ed experienced several incidents where his fleshy body was poorly and disrespectfully treated within caring practices. One of these occurred when two nurses used a hoist to get him out of bed:

*‘...they started putting the strap around me and whatever and I said “you are catching my arm”. They did not hear me, they still kept hoisting me...and my arm was getting further tucked in...I said “don’t do that”...she went buzz buzz [sound of hoist]...I said “d-o-n-’t...d-o...t-h-a-t”’...she did the third time and I said “if you press that bloody thing again” (2nd interview)*

It has been argued that care refers both to a set of tasks and a relation but the one can be present without the other (Watson *et al*, 2004). In Ed’s experience there is a care task - hoisting - yet little evidence of a relationship to him as a person. Hoisting would have involved Ed’s body being touched and physically manoeuvred through the body work of the nurses. Yet it seems that the nurses were treating Ed as little more than an unfeeling object, ignoring his embodied self. In this situation, Ed was doing healthcare, protecting his body by repeatedly trying to direct the nurses’ attention to his trapped arm. But the nurses did not stop until another, more senior nurse, came to chastise Ed for shouting at the nurses.

In another incident it was Ed's sense of appropriate bodily behaviour which came in to conflict with care practice.

*'There was a physiotherapist ...passed by and asked, "How are you doing?" I said, "I am not very well at the moment". He said, "what's wrong?" I said, "Have you noticed what's in front of me?" He said, "Oh Dear, how has that come loose?" I said, "that's my urine bag in front of me and I have asked on 5 occasions for it to be strapped to my leg, could you possibly arrange that" and he said, "certainly" and he bent down and strapped it and I said, "you know what? ...I feel completely different now. I am dignified"' (2nd interview).*

For Ed, the visibility of his catheter bag offended his bodily dignity. In the everyday world, the act of urination is done only in designated social spaces, away from the main public gaze. Having a catheter transgresses the very boundaries of the body: urine in a bag but in front of the body is body matter out of place (Douglas, cited in Twigg, 2000). Ed's offence does not seem to come from concern with what others may think of him. Rather it is about what he feels in relation to his sense of his own body. This conflicts with Twigg's (2000) argument that our disgust with human waste is limited and it is other people's dirt that is of most concern. Ed responded to his offended sense of self by doing healthcare, by drawing attention to his feelings about the placement of the bag. Perhaps what enabled Ed to be persistent in asking for help came from his biographical resources, having been a director of a large health-related public body.

Speculating, one reason the nurses did not respond was that for them catheter bags on display was normal, part of the taken-for-granted world of medical objects which furnish the ward. In this context, perhaps Ed's requests came low down on the nurses' list of care tasks for the day, tasks which become divorced from the individual and subsumed into the doing of the system as a whole (Frank, 2006). The 'complicated network of dependency relations' in hospitals means that time to give attention and non-medical care to individuals is scarce (De Swaan, 1990:38). Hence it was care tasks and not caring relations which were attended to.

These incidents took their emotional toll on Ed causing psycho-emotional effects. To do or process these emotions eventually led Ed to further doing healthcare:

*'I contained my anger for three weeks and in the end I rang up the patients' liaison officer at the [the hospital] and told him for 40 minutes and I am telling you' (2nd interview).*

A number of participants talked about health care encounters which didn't seem to involve any doing of healthcare. In some instances, this was due to the beliefs that participants had about healthcare professionals. This can be illustrated with Suki's experience who was an administrative employee of the NHS. As a patient however, Suki had very little contact with the NHS other than two episodes of emergency neurosurgery to unblock a shunt. On these occasions, Suki felt

*'It was a bit frustrating for me when I couldn't do anything...But when you are in hospital, not working, but as a patient they [nurses] are obviously in the front line. Do as you're told.'* (2nd interview)

At first sight, this suggests that the opposite of doing healthcare is compliance with healthcare professionals' strictures: for Suki this meant passively doing 'as you're told'. However, the fact that Suki experiences being compliant as 'a bit frustrating' indicates a form of emotional doing of healthcare, of experiencing and dealing with her internal sense of frustration. From a Foucauldian perspective, this could be interpreted as an instance of biopower creating her very subjectivity, her sense of what it means to be a disabled person in hospital.

One issue that has emerged here is that in some instances doing healthcare as an in-patient is necessary to protect the body from the consequences of less than ideal care practices. It could be argued that this indicates that having an impaired body in hospital is to be vulnerable and to risk compromising one's dignity and self esteem. Yet the qualities of vulnerability and dignity do not reside in the body per se but in the context in which the body is situated. So, for example, Joel was clearly vulnerable in the incident described above. However, during another hospital stay Joel was not vulnerable because all his impairment needs were met. This happened, Joel felt, because there was a system in place whereby nurses assessed and recorded his needs as soon as he was admitted. Other staff referred to this assessment when caring for Joel. However the point that dignity is context dependent is put most eloquently by another participant, Andrew, a wheelchair user with a progressive

condition. As a child, Andrew had multiple hospital appointments and surgeries and frequently had to strip to his underpants so doctors could view his spine as he walked

*'at the time I didn't feel bad or small or self conscious. But that's the weird thing. What is it that I'm in front of 8 or 9 strangers and I don't feel self conscious? I think one day I could probably walk out the front door and not notice because I'm just so used to being undressed in front of complete strangers. But that is not a good situation. It wasn't that I loss my dignity it was just removed completely, without my wanting it to be.'* (Pilot interview)

What Andrew describes here is the loss of the very possibility of dignity, of his sense of worth and preciousness about his embodied self. It was if Andrew had incorporated the norms associated with clinical practice into his sense of embodied self. In other words, being repeatedly regarded as an object of the medical gaze had colonised Andrew's very subjectivity. As a child, Andrew probably didn't do much healthcare but was extensively "done to".

### ***Doing Healthcare in Relationship with Healthcare Professionals***

French (1994a) notes that many disabled people 'believe that the partnership and collaboration with professionals is important' (115). This was borne out by many participants who endeavoured to establish, reciprocate and sustain good relationships with healthcare professionals. I want to explore how this involved the doing of healthcare by drawing upon the experiences of Frances and Gigi, who were interviewed together. Frances had a rare condition which affected her mobility and was frequently admitted to hospital via casualty. Gigi was a wheelchair user and had episodes of acute hospital admissions and ongoing medical support in the community.

Gigi did healthcare by developing relationships with healthcare professionals based upon a 'partnership model'. This model involves

*'seeing me as the expert in my condition, my needs and my choices'.* (1st interview)

What Gigi highlights is that patient expertise is not just a technical matter of experiential knowledge of how impairment affects the body. Rather it is about the embodied self, about how the individual's preferences and values influence the way

the fleshy body is to be (medically) treated. It is also about what the person wants and is able to do each day to the body and with body, given the social constraints they face and social resources they have. To achieve this through doing the partnership model requires Gigi to ‘handle situations assertively’. Similarly, for Frances doing good relationships with healthcare professionals is

*‘...down to our ability to articulate and to be respected for our opinions.’ (1st interview)*

This communication is something to be worked at, to be developed by ‘learning from one’s mistakes’ as Frances put it. It also, of course, depends upon the responsiveness of healthcare professionals. Frances and Gigi both gave examples of situations where healthcare professionals weren’t responsive or respectful. But they also described situations where it was the healthcare professional who initiated and sustained a strong partnership relationship. When this happened it enhanced the healthcare they received.

Notwithstanding the benefits of partnerships, both Frances and Gigi hinted at the doing it required in the following exchange:

**Gigi:** *‘I kind of feel for... anybody else perhaps with a similar condition to myself... I do try to say that when I have opportunities, it’s not just about me.’*

**Frances:** *‘It’s the old pioneers’ thing.’*

**Gigi:** *‘Of never being off duty.’ (1st interview)*

Here then both women imply they have a connection with and a responsibility towards the wider community of disabled people. By investing their time and skills into maintaining partnership relationships they are ‘pioneers’, what they do is new, beneficial to them, but also leading the way to make things easier for disabled people. But the price of this is ‘never being off duty’ which implies not acting instinctively but doing by purposefully shaping their communication; in short, doing healthcare.



A final point here is that Frances and Gigi had experienced policy and cultural values mediating their relationships with healthcare professionals. For example, Gigi described a situation

*'I had a discussion with one of the district nurses... [she] was questioning my, the quantity of supplies that I was requesting. And I think to be honest she got her sums wrong. But we spoke about it and whilst she was at pains to say, 'I am really just concerned about how you are'. I knew that another kind of trigger factor for her would be, 'we have to keep to a budget here...[I was] just irritated.'* (1st interview)

Here then Gigi is made aware of how the equipment she needed for her daily doing of impairment could be construed as “too much” because there is a budget to be kept to. While this was just irritating it also exposes how quality of life, and indeed support for self management can quickly become reframed as a question of budget, one’s embodiment being too expensive. This intrudes upon the Gigi’s relationship with the nurse. Fortunately the relationship is a strong one. But Gigi has to do healthcare by using her skills to speak with the nurse in a way which restated her needs without jeopardising the partnership.

Frances describes a more subtle, but perhaps more systemic, example of how cultural values about disabled people sometimes hover in the background of healthcare practices:

*'it's the questions that you are asked when you go into hospital and they ask if you are working, what's your job or whatever, and I will always say, I am a retired [professional]. And then now what I say is that I am a member of the[statutory body], but that's a voluntary thing, but I don't say that to them. Its almost like I am saying this to, dunno, to make them think that almost it is, quoting something from somewhere, a life worth living.'* (2nd interview)

In Frances’ doing of healthcare she takes account of a potential grounds for prejudice embedded in the seemingly innocuous question about employment status. Feeling the need to assert her worth she volunteers the information about her position on the statutory body.

## ***Discussion***

In this chapter I have tried to understand disabled people's usage of the NHS using the analytical tool of doing healthcare to take care of the body. This variant of the doing tool has been less successful than those in the previous chapter. It has made it possible to highlight disabled people's agency, the variety of skills they develop and use to get the support they need. However, it is somewhat cumbersome and difficult to always draw out the embodied quality of doing. It has also been difficult to identify the different types of doing healthcare, if it is ever anything other than the ability to be articulate. This may reflect the limitations of the data specifically in that participants were not asked explicitly what they felt that they had to do to secure the healthcare support they needed.

Despite these difficulties, the data analysis presented has highlighted two related surprises. First, it has revealed that some participants have expectations that the NHS should provide more 'reassurance', should 'look after us' or 'call me back for a progress report'. These expectations do not seem easily translatable to a claim for a particular service or approach yet the provision of healthcare professionals who have the time to engage, listen and build up an ongoing relationship might help. However, more research is needed to understand how these expectations emerge, if they are widespread and how they are underpinned by social trends and cultural forces.

Second, the analysis has begun to unpick how embodiment influences the use of the NHS. Experiencing certain qualities of embodiment such as frustration, isolation and profound uncertainty about future embodiment may at times incline people to seek support. These qualities are akin to the existential anxiety (Bury, 1982, S.J Williams 1996), which some have attributed to the onset of impairment. An interesting question here is whether such anxiety, as with qualities of dignity and vulnerability, can be context dependent. Similarly, the analysis has hinted at how medical and nursing practices can have both immediate and long term psycho-emotional effects on embodiment.



## CHAPTER 9

### Discussion and Conclusion

In this concluding chapter, I want to bring together and reflect upon the various strands of this thesis. This thesis set out to understand the social factors which influence disabled people's use of healthcare, and to consider what this may reveal about disability and impairment as sociological phenomena. As it has turned out, the arguments and empirical evidence presented have been somewhat skewed towards the latter aim, understanding of disability and impairment. In effect, exploring disabled people's health care encounters became a case study, a means of exploring impairment in general by examining its meanings in a specific context. Perhaps this skewing reflects the contested nature of disability (G.Williams, 1996), which means one cannot adequately address any specific disability related issue such as healthcare, without first engaging in the more general debate about the nature of disability and impairment. Indeed, Shakespeare (2005) argues that it is precisely because Disability Studies has eschewed impairment that it has had relatively little to say about the positive or necessary role health and medical care plays in disabled people's lives. This thesis has not eschewed impairment. So I will now consider the contribution this thesis makes to Disability Studies by reviewing what has been learnt as a result of engaging with impairment.

### Engaging with Impairment

This thesis began by reviewing Disability Studies' debates about conceptualising and theorising impairment. Although from different theoretical perspectives, work by Paterson & Hughes (1997, 1999), Shakespeare and Watson (2001) and Thomas (2007) all suggests that impairment should be understood as a bodily phenomenon which becomes foregrounded, attributed with meanings, in particular contexts. In different ways, these scholars intimate that impairment is something dynamic, something which emerges from the relationship between the body and social relations and which is never purely social or purely biological. This proposition connects with critical realist perspectives (Shakespeare, 2006, S.J Williams, 1999) which recognises the real, sensate body but also acknowledge that the way we

experience that body is through culture and social relations (Twigg, 2006). But if we take as given that impairment is an emergent property – and I think there are grounds to do so – there is still a need to consider how this is experienced in the body, how it manifests in disabled people’s everyday lives. Similarly, while the argument that impairment is embodied is a significant step forward from the social model which more or less ignores the body, there is still no adequate definition of embodiment, nor a list of its essential components (Turner, 2001). So there is still uncertainty about what constitutes impairment and a lack of fleshy detail about how impairment is experienced phenomenologically.

No doubt, in time refinements will be made to concepts of impairment to increase its specificity and to make it resonate with disabled people’s lived experience. Despite this, there will always be competing concepts and discourses of impairment both within academia and beyond. These often have material effects on disabled people’s lives (see chapter four). It was for this reason that I felt this thesis needed to review how impairment was conceptualised in the context of illness, health and biomedicine. While Disability Studies scholars have already done this in part, this thesis provided an opportunity to do so in significant depth and detail. It was also an opportunity to revisit the literature in the light of criticisms made by these scholars. What then did this conceptual review contribute to the understanding impairment?

Chapters one and two highlighted that impairment, illness and health are all evaluations of bodily states which are mediated through culture and ‘modified by the social categories’ through which they are known (Douglas, 2005:78). Therefore the boundaries between these states are overlapping, contested and negotiable.

Somewhat paradoxically, the grounds where illness and impairment overlap are ripe for exploring subtle differences between these states. For example, during the onset of both illness and impairment, most people reflect upon the body and its symptoms provoking thoughts about “what’s wrong”, and having to deal with the intrusion of bodily experience in the activities of daily life. If an embodied and phenomenological approach is adopted, it may be possible to identify what enables someone to move from experiencing symptoms as disruptive and demanding of bodily attention to becoming taken-for-granted and unnoticed. Conversely, such an

approach could also be used to explore whether some impairment symptoms, for example pain or fatigue, are not transformed in this way. If they were not so transformed, one could then explore whether this is related to the bodily experience of the symptom, the restriction of activities they cause and/or other social variables.

The most significant contribution which this thesis can make to understanding impairment, originated in the literature on the relationship between impairment and health. For my purposes, this literature held two important ideas. First, that understanding impairment in the context of health is a source of positive evaluations of the bodily state of impairment. This suggests that Disability Studies insistence that disability is not a health issue (Barnes, 2003) is something of a missed opportunity. Second, and most importantly, it was the health literature which introduced me to the notion that for some disabled people (and indeed for some non-disabled people), being healthy is something to be worked at, something that required body work. As a result, I eventually came across Mol & Law's (2004) concept of doing the body, and it was from this that the concepts of "doing impairment" and the "enactment of impairment" were developed which and subsequently used to analyse my interview data. I will discuss them in more detail below.

### ***Engaging with Biomedicine***

In a thesis on disability and healthcare, it seemed important, obvious perhaps, to explore biomedicine's perceptions of impairment and some of the ways disabled people's lives become medicalised. This was the purpose of chapters three and four, which also provided an opportunity to explore and contribute to debates about the appropriate roles of medicine in disabled people's lives. However, it was only when I came to analyse my data that I realised that one of the perhaps most significant consequences of biomedicine's understanding of impairment as abnormality is that some participants described how they felt strangely out of place within healthcare settings. For example, despite Fraser's and Joel's best efforts, the nurses just treated them like anyone else and apparently had no procedures to enable them to respond to their impairment and disability related needs. The same was true of the healthcare professionals who interpreted David's movement as caused by childish fear rather

then the access problem of laying on a narrow table, and the doctor who told Andrew that the surgery he was about to undergo would have him ‘up and walking in no time’ yet there was no prospect of this outcome. A common factor behind all these examples is that medical knowledge and healthcare practices seldom engage with the concept of a disabled person, of what it means to have impairment as a condition of embodiment in relationship with a disabling world. Within the medical arena, disability and impaired embodiment are usually eclipsed by the view that impairment is an abnormality, and is so not only in the context of biomedical body, but also in the organisation and practices of healthcare. For example, while there may be good reason for organising services around clinical specialities, in effect, as we saw with Agnes in chapter eight, the complexities of people’s conditions get overlooked as does an understanding of how the totality of someone’s condition impact on their everyday lives. Similarly, some services which are provided for a cross section of disabled people, such as the wheelchair service, are often geographically marginalised on the hospital campus and under resourced: one participant commented that the wheelchairs the service provided him made him feel like a ‘cripple’ and, although cheaper than the superior lightweight chairs, lasted a fraction of the time. Looking to the future, it will be interesting to see if, when complying with the DDA, the NHS embraces the notion of a disabled person and ensures healthcare practices are inclusive and capable of responding to individual need.

### ***Engaging with Impairment Again***

I now want to engage with impairment once more, to consider how my research findings make it possible to elaborate what it means to embody impairment. It is this that I think is one of the main contributions of this thesis to the understanding of impairment. Integral to this elaboration are the concepts of doing and enacting impairment, which I will now discuss.

My research findings suggest that the enactment of impairment refers to both the quality and mode of physical, sensory, emotional and/or cognitive activity. For example, in chapter six we saw that one way in which Fraser enacts his impairment is when he transfers from his wheelchair to his bed. This enactment comprises the technique he uses to transfer, sliding from one surface to another using the power and

strength of his upper body, and the quality of the movement, how his body has to perform physiologically in order to slide in this way.

An interesting question here is whether the enactment of impairment occurs only when someone is actively engaging with the world of objects or participating in social interaction. On the one hand, it could be argued that someone who has a spinal injury, as Fraser does, only enacts impairment when moving. So, for example, when Fraser is absorbed in speaking or reading a book, his impaired embodiment has no effect. This would suggest that impairment is always embedded in a body or cognitive activity, which is always done in relationship with a particularly material context. On the other hand, however, for someone with a condition which results in involuntary movement, their enactment of impairment is continuous, in every moment and context influencing how the body is and what the body does. Yet even if impairment is always enacted whatever the context, the context may nonetheless influence the enactment, for example how the impairment is enacted when eating will be different from how it is enacted when at rest. A similar argument could be made about impairments where the main symptoms are pain or mental distress. Of course, in enacting impairment, the individual will not necessarily be aware of their body: once the techniques and associated phenomenology of enacting impairment is mastered and accommodated, the body may be once more taken-for-granted. Yet the quality of this taken-for-grantedness may not be the same as that experience of a non-disabled person when doing the same activity. A non-disabled person may just jump in the shower, bracketing out all bodily awareness of the physical movement involved. Yet, complete bracketing out movement may not be possible for a disabled person for whom showering is effortful, time consuming or who needs to make a conscious effort to be aware of what bodily techniques are needed to avoid falling (Tichkosky, 2002). There is scope for further research here to identify the different degrees and types of awareness of the body which people experience when enacting impairment.

One of the strengths of the concept of enactment of impairment is that it is descriptive rather than normative. It does not imply or require a biomedical understanding of the body yet it acknowledges that impairment influences how the



body can be and the ways in which it can act. Indeed, the discipline of trying to describe or specify how impairment is enacted, how the embodied self experiences and shapes this enactment, distracts one from the temptation to compare the impaired body with a non-impaired one. Further, whatever the particularities of impairment, its enactment is never just a matter of biology: it is always influenced and mediated by other facets of embodiment, and those facets are always socially and culturally mediated. All this strengthens the case of those who call for a phenomenology of impairment (Hughes & Paterson, 1997, Watson, 2000, Wendell, 2003). However, the danger of such an approach is that it neglects the social, is individualistic (Turner, 1991) and becomes purely descriptive. To avoid this, attention would need to be paid to how social relations mediate the enactment of impairment.

The second bodily process that is integral to embodying impairment is doing impairment, the embodied self reflexively attending to, and acting upon, the body in order to meet its needs. The notion of doing impairment provides a means of specifying the bodily related tasks which disabled people have to do due to the condition of their body and the social and cultural relations in which their bodies are enmeshed. Thus critical to the value of doing impairment is the need for deconstruction: for any given bodily task that impairment necessitates, it is imperative that the different layers of doing impairment are identified and explored. This ensures that the concept moves beyond the descriptive and starts to unravel the broader cultural and social influences on doing impairment. These influences shape the need for bodily doing, how the doing is done and the constraints which limit or prescribe how the doing of impairment is done.

The concept of doing impairment also enables us to specify that one facet of impairment is that it is a series of activities. The necessity to do those activities emerges from the relationship between the characteristics of the embodied self and the social and cultural world. This specification captures disabled people's agency at the same time as showing how that agency is circumscribed by social structures, relationships and personal biography. It does so by quite literally trying to pinpoint not only the physical tasks that the embodied self does to the impaired body, but also the emotional and cognitive ones. In turn, this makes it possible to draw attention to

and explore the various types of body and disability related “work” that disabled people have to do. This work begins with body work but, as we have seen, also includes bureaucratic doing, handling access and doing healthcare. Acknowledging this work is important both theoretically and politically because it highlights that barrier removal alone does not necessarily lead to a level playing field between disabled and non-disabled people. This is particularly important in the context of debates about employment and what some may regard as schemes or services which some see as conferring “privileges” upon being disabled people. A good example of the latter is the “Blue Badge” scheme, which in effect, compensates those that enact their impairment in a way which reduces mobility. In both these instances, policy has to have regard of how doing impairment in itself is restrictive for certain people, in certain social contexts.

### ***Embodying Impairment***

Taken together, the concepts of doing and enacting impairment can be seen as two processes which constitute the embodiment of impairment. Embodiment comprises both constraints and ‘opportunities which are endlessly elaborated through sociocultural and historical development’ (Williams & Bendelow, 1998:10). Similarly, both doing and enacting impairment constrains and provides the possibilities of who one can be and what one can do. Thus they can be understood as conditions of embodiment. The term “condition” here does not refer to the diagnostic labels used to describe or categorise a cluster of symptoms. Rather, it is used in the legal sense of being subject to certain conditions. Hence what the embodied self can be and do becomes subject to the proviso of impairment. So if embodiment refers to how we perceive and engage in the world through and with our bodies (Csordas, 1993), then impairment as a condition of embodiment influences that perception and engagement. The form that influence takes will depend in part on the type of impairment, how it is manifested in and through the body, how it structures movement, communication, emotions and so forth.

Central to understanding impairment as a condition of embodiment is that impairment is always one of many possible conditions of embodiment. Other conditions of embodiment include physicality, emotional state, the capacity to reflect

upon ourselves and chronological age. So, for example, age conditions how the embodied self can be and do: a baby's condition of embodiment means she has to be carried up the stairs, a youngster's condition of embodiment allows him to bound up the stairs, perhaps two stairs at a time when exuberant, while an older person may have to take time and find the activity exhausting or unsettling due to the fear of falling. Here then, the idea of impairment as a condition of embodiment facilitates consideration of the way any particular type or instance of impairment conditions the body, as well as how it interacts, how it influences and is influenced by other conditions of embodiment. In short, conceiving of impairment as a condition or dimension of embodiment facilitates analysis of the diversity of impairment, diversity both in terms of different forms of impairment and other conditions of embodiment. Therefore it allows for a subtle exploration of how a myriad of conditions of embodiment interact and produce a particular constellation of embodied experience.

But embodiment isn't just about the state of a body abstracted from the world. Rather, embodiment locates human beings as emerging from the intersection between the body and social structures (N.Watson, 2000). So impairment as a condition of embodiment is always shaping and being shaped by the relationship between the embodied self and the social world. This translates into an understanding of impairment which is similar to the critical realist position described above: in other words impairment as a condition of embodiment emerges from the relationship between the embodied self and the social world. This relationship is dynamic insofar as the moment impairment emerges it becomes a somatic mode of awareness (Csordas, 1993). Hence embodiment is always an ongoing process and something that always has to be accomplished (Turner, 2000).

For example, as a wheelchair user approaches a heavy door, a barrier created by the combination of her embodiment and the design of the door (see chapter seven), and thwarts her progress. As well as feeling excluded or frustrated, she also has to consider how to handle the access problem. So she may attempt to open the door, feeling its weight against her arm, she may experience the awkwardness of moving the chair out of the path of the opening door, hear the noise of the chair's footplates

banging against the door, evoking fear that the glass may break, with all the consequences that may have on both the physical and emotional embodied self. Here then, we get a second sense of impairment as dynamic: the experience of disabling barriers has ramifications for a number of conditions of the body and shifts the experience of future embodiment. This in turn will condition how people handle access on a subsequent occasion. Indeed Imrie & Kumar's (1998) research found that some disabled people avoid going out all together rather than face access handling.

### ***The Limits of Doing***

Notwithstanding the benefits and potential of the concepts of enacting and doing impairment, an important question which requires further thought and more empirical research is how far to develop the concept of doing impairment and in what contexts it could provide useful analytic purchase. In chapter seven, the concept of handling access was derived from doing impairment. This concept made it possible to begin to specify the types and range of interactional work disabled people have to do when they encounter, or when they try to avoid encountering, disabling barriers in healthcare settings. The concept also made it possible to consider the embodied consequences of access handling, including its psycho-emotional effects, and how it impacted upon relationships with healthcare professionals and the wider public. This, I think, makes a useful contribution to the understanding of access issues, firstly by exploring the barriers which are unique to healthcare settings and second by providing insight into how particular individuals experience and handle access barriers.

Particularly important in this regard was clinical access. Although this was identified as a problem for only two participants, it was here that the tension between different understandings of impairment in a medical encounter became particularly evident. What came to the fore here was healthcare professional's apparent difficulty in recognising how the embodiment of impairment is influenced by the situation in which it is being enacted at any moment in time. This led to misinterpretations of participants' actions and a reluctance or inability to discuss the role environment and social context have in influencing the outcome of diagnostic procedures. In part,

what lay behind these misinterpretations are the biomedical understanding of the impaired body, which was discussed in chapter three.

In chapter eight, I extending the concept of doing once more, this time looking at how disabled people “do healthcare” in order to take care of their bodies. In the context of participants’ expectations of the NHS, this enabled me to touch upon the isolation and anxiety which can arise when impairment is a condition of embodiment and participants’ feelings that they wanted the NHS to look after them. In some senses, these issues are anathematic to Disability Studies not least because of its opposition to the medicalisation of disability, leaving it instead to Medical Sociology to do so (see, for example, Bury, 1982, S.J. Williams, 1999). For me, the advantage of the concept of doing healthcare was that it could capture not just the fact that participants had these feelings but also how they wanted to, and how they did, engage with them. It also became apparent that the amount and type of healthcare doing required was nearly always contingent upon the practice of healthcare professionals: when a participant regarded a health care encounter as “good” it often meant that he did not have to “do”, they were content to be done unto. This suggests there is a need for further research to identify what stops healthcare professionals responding to the impairment-related needs of disabled people, and the role policy and institutional context play in this. There is also a need to explore how healthcare professionals’ understand and interpret disabled people’s doing impairment and doing healthcare and whether this influences professional practice.

### ***Doing Impairment and the Bigger Picture***

How then can the concepts of enacting and doing impairment relate to other theoretical approaches within Disability Studies? Carol Thomas’ (1999, 2007) concept of impairment effects, especially as formulated in her later work, describes impairment related restrictions of activity that are contingent upon the biological together with social and cultural forces. This is very similar to what I am proposing save that, as I use the term, condition is not medically rooted, which is not the case with impairment. Nonetheless, the similarity forces me to consider what Thomas does not – if impairment emerges from the relationship between conditions of embodiment and the social space and interaction, what’s the difference between

impairment and disability? To be honest, in writing this and the previous three chapters, I have often dithered about when to use impairment, and when disability. Clearly, it makes sense to talk about impairment when doing impairment involves the embodied self acting upon the body, such as checking skin on pressure areas. However, things become less clear when talking about doing bureaucracy or handling access: aren't they doing disability by virtue of the fact that they involve dealing with social barriers? My sense is that the advantage of calling these doing impairment, not doing disability, is that it makes it easier to emphasise the embodied nature of doing. But I acknowledge that this argument is a hang over from the social model of disability, where impairment is related to body and disability to social structures. However ultimately I think that if there is a difference between disability and impairment, it is a difference of degree rather than of kind. That is, disability also emerges from the relations between embodiment and social space or interaction, but the barrier or restriction is one experienced by many, and which can be removed by a solution without reference to anyone's particular embodied needs. In effect, what I am describing here is the difference between macro and micro access needs, defined in chapter seven. Perhaps those concepts that can be used to differentiate doing impairment from doing disability.

There is also much theoretical work to be done to consider more deeply if and how doing and enacting impairment can be connected with social theory which considers the nature of the human embodied being and its relationships with society. For example, Jonas (2005) argues that, as living organisms, human beings can be only if we do. The work of both Elias and Mauss are concerned with the way we learn to use our bodies and the connection between body habits and behaviour (Williams & Bendelow, 1998). Similarly, by drawing upon phenomenological traditions, it may be possible to understand better the bodily experience of physical, emotional and cognitive doing. This may lead to more subtle understandings of the boundaries between impairment, health and illness.

### ***Final conclusion***

In some ways, these final concluding remarks feel as much like a new beginning as an ending. What this thesis has done is to put down some markers for fresh ways of

investigating familiar but contested topics. Of these topics, impairment as a condition of embodiment seems the most important, but that of the relationships between impairment and health and the nature of body work are significant too. Although this thesis has been weighted towards theoretical and conceptual issues, implicit within it are some implications for policy and practice too. However, what is depressing is most of these have a very familiar ring to them, suggesting the need for creative thinking to come up with innovative solutions. They include:-

- What training and support systems need to be in place to enable healthcare professionals to be responsive to disabled people's micro or individual access needs?
- What services or support systems are needed by those who feel they get too little support from the NHS?
- Is there a need for advocacy services to support and encourage the development of true partnership relations between disabled healthcare users and healthcare professionals?

These and similar issues will be further explored and documented. They will then be presented to ECAS who funded this PhD. But the final word must go to one participant, Elspeth, who I asked what impact her impairment made on her everyday life:

*"It does give you something else in your 'to do' list". (2nd interview)*

Impairment then must be done.

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## APPENDICES

### *Appendix 1 – Channels of Recruitment*

Impairment Support Group	7
Personal Contact	11
Snowballing	2
Edinburgh Council Equal Opportunities Group	3
Local Disability Group	1
Local Newspaper Advert	3

Total Number of Participants = 27

## **Appendix 2 - Questioning the Data**

Themes	Questions	Code
<p>Embodying impairment, disability &amp; health</p> <p>Impairment hierarchy</p>	<p>How do disabled people talk about impairment/their body?</p> <p>Are emotions implicated in an embodied impairment? How?</p> <p>Does medical care influence embodiment?</p> <p>Does medical discourse and practice influence the experience of impairment?</p> <p>How do disabled people talk about the relationships between impairment, disability &amp; health?</p>	<p>Q1/body talk</p> <p>Q1/emotion</p> <p>Q1/med imp</p> <p>Q1/imp rel health</p>
Responsibility	<p>Expertise</p> <p>Are disabled people ‘experts’ when it comes to handling relationships with health care professionals? What forms does this ‘expertise’ take?</p> <p>What factors influence the development of expertise?</p> <p>Does patient expertise conflict with health care professionals’ expertise?</p>	<p>Q2/eg expert</p> <p>Q2/inf expert</p> <p>Q2 conflict</p>
Responsibility	<p>In health care encounters, is there a struggle to control the body? What are the boundaries between disabled people and health care professional control?</p> <p>In the context of control struggle, what is the significance of diagnosis</p> <p>Who takes responsibility for caring for and tending the</p>	<p>Q3 Struggle</p> <p>Q3 Diagnosis</p>

Responsibility	impaired body? What does this involve? Does it vary, if so, how?	Q3 tending
Responsibility	What roles do GPs play in helping disabled people to manage their impairment? Do those roles meet disabled people's needs?	Q3 role of GP
Impairment solidarity	What is the importance of impairment specific groups/impairment solidarity in relationship to disability and health?	Q4/solidarity
Healthcare Professionals	Qualities  For disabled people, what qualities make for a good health care professional? Does it vary according to type of health care professional?	
Access	What is the range and type of access problems disabled people face in health care contexts?	Q5/ access issues
Responsiveness	What factors shape access issues in the health care context? Are some access issues unique to health care context?  Who takes responsibility for dealing with access issues in health care contexts? How? What does it involve?	Q5/access in health  Q5/handling

### ***Appendix 3 – Information Leaflet for Disabled People***

Would you be willing to help?

What's the research about?

The research is about disability and health care. It aims to find out about disabled people's experiences of using the NHS, particularly primary health care services such as GPs, Dentists and District Nurses.

What would be involved?

Being involved would mean agreeing to be interviewed by Ruth Bailey, a disabled student at Edinburgh University. The interview would be like an informal discussion, with Ruth asking you about your experiences of using the NHS and whether you feel disability has influenced those experiences.

The interview would take place on a day and at a place which is convenient for you. It would take about 1-1½ hours and, if you give your permission, would be recorded.

Who can take part?

Any disabled person living in Edinburgh who is aged between 18 – 65.

What's the research for?

The research is being done as part of Ruth's PhD, funded by ECAS (Equality Choices Action and Support). The results of the research will be made available to disabled people.

How can I find out more?

Contact:	Ruth Bailey
By email:	<a href="mailto:R.Bailey-2@sms.ed.ac.uk">R.Bailey-2@sms.ed.ac.uk</a>
By phone:	07944 056197 / 0131 650 3990
By post:	Room 119, Adam Ferguson Building, George Square, Edinburgh, EH8 9LL



#### **Appendix 4 – Consent Form**

Please read the statements below. If you agree with the statement, please tick the appropriate box. If you disagree, please leave the box blank.

I agree to take part in this study of Disabled People's Health Care Encounters and am happy to talk with Ruth Bailey about my experiences of using the NHS. ☐

I agree that Ruth Bailey can inform my GP that I am participating in this study using the letter that is attached to this form, ☐

I understand that I can withdraw from the study at any time and that I don't have to answer any questions I don't want to. ☐

I know that any health care services I use will not be affected in any way whether or not I take part in the study. ☐

I understand that anything I say to Ruth Bailey will be treated in the strictest confidence. ☐

I understand that if any comments or views I express are quoted or referred to in any report of the research, my name and my personal details will be changed so that my identity won't be revealed. ☐

I give my permission for the interview to be recorded. ☐

Name .....

Address .....

Postcode .....

Telephone number: .....

Signature .....

## **Appendix 5 – GP Letter**

Community Health Sciences (Public Health Sciences Section)

Teviot Place

Edinburgh EH8 9AG

Email: [R.Bailey-2@sms.ed.ac.uk](mailto:R.Bailey-2@sms.ed.ac.uk)

Telephone: 0131 651 3977

Dear

Disabled people's health care encounters

I am writing to inform you that one of your patients has agreed to be interviewed for a research project exploring disabled people's experiences of using primary health care.

The details of the patient involved are

Name .....

Address .....

.....

Date of birth .....

The research project is part of my PhD studies at the University of Edinburgh. It aims to explore some of the factors which influence disabled people's experience of using Primary Health Care in Edinburgh.

If you want further information about the project, please do not hesitate to contact me.

Yours sincerely

Ruth Bailey

## ***Appendix 6 – Topic Guides***

### **FIRST INTERVIEW**

#### ***Q1: MAPPING USE OF HEALTH SERVICES***

##### **AIMS:**

To encourage people to talk about their healthcare experiences

To find out range of services used and what influences / constrains pattern of use

##### **MAIN QUESTION:**

When did you last use the NHS?

##### **PROBES:**

For range of experiences

Have there been times in your life when you have had a great deal of contact with the NHS? Are there any NHS services which you use regularly?

For range of services used

GP, practice nurse, district nurse, physio, dentist, opticians, alternative health practitioner, preventive health screening, pharmacy, OTs, counselling

For depth

What happened? How did it feel? What was that like? What made it good / bad?  
What about other times?

##### **ROUND UP QUESTION:**

Are there any types of health service that you want but are not currently getting?

Is there anything else you wanted to say about NHS services?

#### ***Q2: ACCESS ISSUES***

AIMS:

To identify range of access problems disabled people experience, how the problems are handled and whether Disability Discrimination Act has reduced problems.

MAIN QUESTION:

Have you ever had access problems when using the NHS?

PROBES:

For types of access problems

Transport, parking, getting in to building, getting round the building, getting information, transferring/getting on to examination couch, in diagnostic setting, in the ward?

For depth

What happened? How did you manage? What was it like? Did you talk to someone about this? What should have happened? Did you complain? Have you come across that before / since? Did it affect your use of services / the quality of service / type of treatment you had? Did it affect the relationship you had with health care professional?

ROUND UP QUESTION

Has access improved since the DDA? In what ways?

Is there anything else you want to say about access?

### ***Q3: RELATIONSHIPS WITH HEALTH CARE PROFESSIONALS***

AIMS:

To understand what sort of relationship disabled people want with a range of health care professionals and what helps and hinders the formation of such relationships.

MAIN QUESTION:

How do you get on with your GP?

PROBES:

For depth:

What's good / bad about the relationship? Has it always been like this? Is it important to you to have a good relationship? Why? Has it got anything to do with being disabled? Is there one particularly good relationship you have had with a health care professional either now or in the past? What made it good?

For range of health care professionals:

What about relationships with other health care professionals – example consultant / nurse / OT / physio?

SECONDARY QUESTION:

Some disabled people say some health care professionals have negative attitude towards them. Is that something you've experienced? Can you tell me about it?

Is there anything else you wanted to say about health care professional relationships?

***Q4: MEDICALISATION***

MAIN QUESTION:

Some disabled people say they often have to see the GP for administrative reasons, example to sign a claim for benefit form or to get 'proof' of their disability status? Is this something you've experienced? Can you tell me about it?

PROBES:

For depth:

How did you feel about having to do that? Do you think it should be like that? Was the Doctor OK about doing that?

ROUND UP QUESTION:

In your experience have healthcare professionals told you about other services or sources that you may need?

## SECOND INTERVIEW

### ***Q1: MANAGING HEALTH***

#### AIMS:

To find out what support disabled people receive to enable them to manage their health / impairment and whether they think it is adequate / appropriate.

#### MAIN QUESTION:

What do you do if you have a health problem which is connected with your disability? Who would you go to for help?

#### PROBES:

For depth about type/nature of support:

Is it important to you to have regular check-ups? Why? Why not? Who with? In what ways are they helpful? / unhelpful? Is there one specialist who you know you can go to if there is a problem? Ideally, would you want more support than you're getting? What type of support? Have you discussed it with anyone? Has there been a stage in your life when you did get regular support? What was that like?

How often do you get these problems? Does it mean you on-going contact with the NHS? How is that? In what ways does it influence the rest of your life?

### ***Q2: MANAGING HEALTH***

#### MAIN QUESTION:

Some disabled people say that when they get sick, health care professionals assume that it's something to do with their impairment. Is that something you've experienced? Can you tell me about that?

PROBES:

For depth

What did you think about that? What did you do? How did it make you feel? Have you seen that person again? How did that go? Have you experienced anything like that since?

***Q3: EXPERTISE***

MAIN QUESTION:

Who has expertise about your condition?

PROBES:

For depth

Can you give me some examples of expertise? What's important about that? What about your own expertise? How have you developed that? Is your expertise recognised? How? Has it caused conflict between you and health care professionals? What happened? How did you handle it?

For scope

What about with other health care professionals such as OTs, physios? Have you been in a situation where they've told you 'they know best'? What happened? How did you feel about that?



